Does Harvey's (2002) cognitive model of insomnia predict sleep disturbance among older adults with mental health problems?

By

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Volume 1

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INTRODUCTION TO THE PORTFOLIO

This portfolio contains a selection of work completed during the PsychD in Clinical Psychology.

Volume 1

This volume comprises the academic dossier, containing five essays, the clinical dossier, containing summaries of the five clinical case reports and summaries of clinical placements, and the research dossier. This contains the service-related research project, literature review, research logbook, and major research project. Within each section, work is presented in chronological order.

Volume 2

This volume comprises the five clinical case reports carried out on placement as well as other placement information, including placement contracts, logbooks of clinical experience, examples of correspondence written on placement and placement evaluation forms. Information is presented in relation to the placement it pertains to, and each placement is presented in chronological order. Due to the confidential nature of the material in this volume, it will be kept in the Psychology Department at the University of Surrey.

The portfolio aims to highlight the range of experience obtained during the PsychD course, and reflects the variety of clinical, academic and research competencies developed over the three years.
ACADEMIC DOSSIER

OVERVIEW

This section contains four essays completed during the first two years of training. Three were written regarding core client groups, and one on a specialist topic of the trainee's choice. These essays critically evaluate the theory and practice of a variety of psychological issues for individuals of all ages.
Adult Mental Health Essay

Compare and contrast the effectiveness of cognitive behaviour therapy and systemic therapy in the treatment of eating disorders.

Dec 1999
Year 1
Compare and contrast the effectiveness of cognitive behaviour therapy and systemic therapy in the treatment of eating disorders.

Introduction to eating disorders

The most prominent eating disorders in psychologists' research have been anorexia nervosa and bulimia nervosa, to be known throughout as anorexia and bulimia. The American Psychiatric Association's Diagnostic and Statistical Manual of mental disorders (4th edition, DSM-IV) also includes 'Binge-Eating Disorder' as a provisional diagnosis (Arnow, 1999) and 'Eating Disorder Not Otherwise Specified'. Fonagy and Roth (1996) explain that this category is used to describe "subthreshold" cases, where criteria for the other eating disorders are only partially met.

DSM-IV lists the following criteria for the diagnosis of anorexia: refusal to maintain body weight at more than 15 per cent below normal weight for age and height; intense fear of gaining weight or becoming fat; disturbed perception of body weight, size or shape; and the absence of at least three consecutive menstrual cycles. Whilst these focus on cognitive and physical functioning, Bryant-Waugh and Lask (1995, p.14) note that the following behavioural and psychological features are common: "activities designed to avoid weight gain...perfectionism, obsessive-compulsive behaviour, poor self-image and marked mood disturbance, with depression being not uncommon".

The following criteria are listed in DSM-IV for the diagnosis of bulimia: episodes of binge-eating which are accompanied by feelings of loss of control; behaviour intended to prevent weight gain such as self-induced vomiting, misuse of laxatives or excessive exercise; and undue influence of body shape and weight in self-evaluation. Diagnosis requires the behaviours to be evident at least twice per week for three months. Bryant-Waugh & Lask (1995, p.14) note the frequent comorbidity of "mood disorder, particularly depression, and impulsive and self-harming behaviour such as chemical misuse, overdosing and self-mutilation". The overlap of symptoms between the two disorders is resolved by anorexia having 'diagnostic primacy' (DSM-IV).
The diagnostic criteria demonstrate that both disorders pose significant risks of harm for those affected, indeed several authors report mortality statistics (e.g. Hsu, 1980, p.1042; Minuchin, Rosman & Baker, 1978, p.127). Fonagy and Roth (1996) provide prevalence figures of between 0.5% and 2% for anorexia and between 1% and 3% for bulimia. Prevalence data vary between authors (e.g. Bryant-Waugh & Lask, 1995) according to such factors as diagnostic criteria and identification method, and can therefore only be used as estimates. Bryant-Waugh and Lask (1995) note variations in the prevalence of anorexia across cultures and professions. Russell, Szmukler, Dare and Eisler (1987) report that the incidence of anorexia is rising. It is well established that prevalence amongst females is much higher for both disorders (Arnow, 1999; Bryant-Waugh & Lask, 1995; Fonagy & Roth, 1996).

Aetiological models of anorexia and bulimia have considered a range of possible influences, and often include genetic susceptibility, cultural values, personality disturbance, familial functioning, abusive sexual experiences (Bryant-Waugh & Lask, 1995), psychoneuroendocrine factors, distorted cognitive processing and restrained eating patterns (Arnow, 1999). This essay will discuss cognitive-behavioural and systemic models.

Cognitive behaviour therapy (CBT) and systemic therapy have both been used to treat anorexia and bulimia though outcome is often poor. Among anorectics, Arnow (1999, p.671) cites review data which reports approximately 40% recovery following treatment, residual symptoms in 33% and chronicity in the remainder of cases. He notes that anorectics' resistance to gain weight must be addressed in order for treatment to be effective. Bryant-Waugh and Lask (1995) report persistent symptoms in approximately 30% of bulimics following treatment. In the evaluation of treatment studies, at least the following factors appear to be influential: sample recruitment method; inclusion criteria; treatment outcome measures, and length of follow-up.
Introduction to CBT

The cognitive behavioural approach considers faulty cognitive processing to be causal in the development and maintenance of dysfunctional emotional and behavioural functioning. Thus, Thompson (1999, p.44) writes: “the apparently bizarre and irrational behaviour observed in anorexia is the direct result of a set of beliefs, attitudes and assumptions about the meaning of body weight”. However, Fairburn and Cooper (1989, p.279) state that “most features of anorexia and bulimia appear to be secondary to the patients’ extreme concerns about shape and weight” and acknowledge that “this prediction has yet to be tested”.

Hollin and Lewis (1988, p.111) state that assessment interviews and observation should consider “aetiological factors, present behaviours and cognitions and the reinforcing consequences”. They also argue that issues originating in the past should be resolved during treatment to enhance aetiological research and avoid later symptom substitution. This contrasts with Hawton, Salkovskis, Kirk and Clark’s (1989) report that CBT usually focuses on ‘the here and now’. CBT’s emphasis on scientific methodology is evident in therapists using psychometric scales and operationalising symptoms and treatment goals in objective, measurable terms when assessing problems and measuring change.

Cognitive behaviour therapists use a combination of cognitive and behavioural techniques. In the treatment of eating disorders, these might include: socialisation into the CBT model; self-monitoring of eating-related cognitions and behaviour; education regarding body weight and the effects of dysfunctional behaviour; behavioural modification of eating habits; identification of, challenging and restructuring dysfunctional cognitions; and relapse prevention (Fairburn and Cooper, 1989). Behavioural change is deemed an insufficient outcome, cognitive-behaviour therapists aim also to elicit more adaptive cognitive processing.
CBT for Bulimia

Freeman, Barry, Dunkeld-Turnbull and Henderson (1988) compared CBT to behaviour therapy (BT) and supportive and educational group therapy with a sample of 92 adult women who met DSM-III-R criteria for bulimia. The authors do not report how participants were recruited or their mean duration of symptoms prior to treatment. All treatments were conducted in 15 weekly sessions of one hour duration. At the end of treatment, 77% of the sample had stopped bingeing whereas a waiting list control group demonstrated no significant change. Comparison of the different treatments showed that BT was most effective across a range of outcomes, operated most quickly and had the lowest drop-out rate.

This contrasts with later work, which has demonstrated more positive results from CBT than BT. Fairburn, Jones, Peveler, Carr, Solomon, O’Connor, Burton and Hope (1991) compared BT, CBT and interpersonal psychotherapy (IPT). BT focused on normalising eating patterns. IPT was chosen as “a credible alternative to CBT since the interpersonal functioning of patients with bulimia nervosa is often disturbed” (Fairburn et al, 1991, p.464) and used psychodynamic principles to focus on current circumstances, addressing interpersonal difficulties without reference to eating patterns.

Participants’ mean age was 24.2 years, and the mean duration of symptoms prior to treatment was 4.4 years. Although the authors argue that their sample is likely to be typical of patients seen by general practitioners and psychologists, they requested referrals for inclusion in a research study which may have influenced referrers. Their assessment demonstrates poor adherence to DSM-III-R criteria; 9 of the 75 participants did not show excessive concern for shape and weight, and 9 did not vomit or misuse laxatives. Whether these participants used alternative methods to prevent weight gain, thereby meeting DSM criteria, is not reported. The laxity of these criteria would seem to reduce generalisability of results from this study.
All treatments consisted of 19 sessions of 50 minutes duration and lasted for 18 weeks, with the frequency of sessions decreasing over this time. All treatments were associated with significant improvements at the end of therapy in overeating frequency, laxative misuse, weight gain, psychiatric symptoms and social adjustment. Across treatment groups, binge-eating frequency decreased from a mean of 16.5 episodes per month to 1.2. CBT was associated with the greatest improvements in dietary restraint and attitudes to shape and weight. CBT and BT demonstrated approximately equal decreases in vomiting. Although participants' reports of treatment acceptability did not differ, BT demonstrated the highest attrition rate and IPT the lowest.

Each of the 6 therapists administered only one type of therapy, it is not stated how they were allocated to therapy type and differences between therapists are not examined. As "it is often difficult if not impossible for researchers...to be blind to treatment assignment" (Mitchell, Raymond & Specker, 1993, p.244) it seems important to control individuals' training histories and therapy preferences.

Fairburn, Jones, Peveler, Hope and O'Connor (1993) provide a one-year follow-up of the data presented above. Improvements in vomiting, over-eating, dietary restraint, attitudes toward shape and weight and psychopathology were either maintained or continued to improve across this time period. There were no significant differences between the effects of CBT and IPT at this stage which suggests approximately equal effectiveness, although it is noteworthy that CBT operated more quickly. Arnow (1999) suggests that this equivalent effectiveness may be attributable to non-specific therapeutic ingredients - "a positive therapeutic alliance, creating a rationale that the client accepts, generating positive expectancies, and attenuating demoralisation" (Arnow, 1999, p.672) yet this does not explain the poorer results among those who received BT, where it can be assumed that these factors were also present.

Follow-up was 'closed', meaning that participants were unable to receive further treatment "unless...judged necessary on clinical grounds" (Fairburn et al, 1993, p.422). Although additional treatment is an important variable to control, it is not reported
how this was communicated to participants and whether they found it acceptable; clearly to be ethical, this requires sensitivity.

Data from this sample were again analysed by Fairburn, Norman, Welch, O'Connor, Doll and Peveler (1995) in conjunction with data from an earlier study. Of a possible sample of 99, 91 participated. Although 2 of the remaining 8 were apparently untraceable, it is important to consider why some participants declined. In the study described above, Freeman et al (1988, p.524) found that “some patients were very resistant to follow up when they perceived themselves to be cured and others when they had lapsed after successful treatment”. Hsu (1980) supports the second possibility, noting reduced compliance with follow-up among anorectics with continuing symptoms.

Fairburn et al (1995) reported that 41 participants met DSM-IV criteria for diagnoses of bulimia, anorexia or ‘eating disorder not otherwise specified’. This is consistent with Bryant-Waugh and Lask’s (1995) report that a significant proportion of bulimics remain symptomatic after treatment. As evidenced by the proportion of participants in remission, CBT and IPT were again associated with significantly more improvement than BT. As at one year follow-up, there were no significant differences between CBT and IPT.

No effect of length of follow-up was obtained in this study, which suggests that change was well maintained from the first year after treatment, although some changes were apparent. Perhaps unsurprisingly, prognosis for those in remission at the end of treatment was considerably more optimistic than for those who were still symptomatic at this time. However, improvement following the end of treatment was also evident; 12 of 51 not achieving remission during treatment were in remission 12 months later and by later follow-up this figure increased to 21 of 51. There was also some, lesser, evidence of deterioration, 4 of 38 in remission at the end of one year became symptomatic by later follow-up.
Walsh, Wilson, Loeb, Devlin, Pike, Roose, Fleiss and Waternaux (1997) contrasted CBT and individual psychodynamically-oriented supportive psychotherapy. All participants were also prescribed anti-depressant medication or a placebo. Participants were recruited via media advertisements, which might reflect increased insight and motivation for treatment. All had met DSM-III-R criteria for bulimia for at least one year, and vomited to prevent weight gain. Although researchers do not appear to have addressed this issue, the possibility of differences between bulimics who vomit and those who use other compensatory methods cannot be ruled out. Both forms of psychological intervention offered 20 sessions of unspecified length over 16 weeks but those receiving medication only had less contact with the researchers.

At the end of treatment, CBT was the most effective intervention in the reduction of binge-eating and vomiting, and improvement of attitudes towards shape and weight, although statistical analysis did not control for multiple comparisons. Support for psychological intervention was also obtained via participants' perceptions of treatment relevance, and was evident in higher attrition among those receiving medication only.

Those receiving CBT and anti-depressant medication achieved 67% remission from binge-eating whilst those receiving CBT and placebo achieved 38% remission. The lack of a CBT only subgroup hinders consideration of this effect. This discrepancy was not evident among those who received supportive psychotherapy, where the medication and placebo subgroups each achieved 29% remission from binge-eating. In view of the change in treatment effectiveness across time noted by Fairburn et al (1993), it is disappointing that no follow-up data are available for this study.

To summarise, CBT has been associated with significant improvements in bulimic symptomatology and appears superior to anti-depressant medication, supportive psychotherapy and, in the short term, IPT. However, the significant numbers of participants remaining symptomatic after treatment, demonstrate the inadequacy of its effectiveness. Across time, it appears that CBT and IPT may be equally effective in the treatment of bulimia.
CBT for Anorexia

Although cognitive behavioural models accounting for the development and maintenance of anorexia have been proposed - see for example Fairburn, Shafran and Cooper's (1999) model which integrates concern for shape and weight with self-control - Wilson (1999, p.82) writes that “adequately controlled studies of CBT for anorexia have been conspicuously lacking”. He cites two studies, both of which employed small samples. Neither study demonstrates the effectiveness of CBT over BT, eclectic therapy or behavioural family therapy for anorexia. Wilson (1999, p.82) notes “the difficulty of recruiting sufficient subjects given the low prevalence of the disorder” yet adequate numbers have been recruited to the evaluation of systemic therapy. The overlap of symptoms between anorexia and bulimia suggests that CBT may be an effective treatment for anorexia, yet their differences require this assumption to be empirically validated.

Introduction to systemic therapy

At this point, it is important to acknowledge that there are different schools of systems theory (Bryant-Waugh & Lask, 1995, p.24). However, due to constraints of space and published research relating to eating disorders, this essay can only focus on general characteristics of systemic family therapy. This is supported by Bryant-Waugh and Lask’s (1995) statement that no school of family therapy has been identified as more effective than others in the treatment of eating disorders.

The focus of systemic work is “the individual in context” (Minuchin, Rosman & Baker, 1978, p.10). Eisler (1988, p.98) describes the scope of systemic therapy as broader than CBT, considering “the behaviour of each person, not just as an expression of that individual, but also as an expression of the role that he holds in the given context, and of his relationship with other people” and notes that “events, feelings and beliefs in the present are intertwined with both the past and the future”. Whilst this includes emotions and beliefs, it adds roles and relationships, and past experiences, which receive less attention in CBT.
Whereas cognitive behaviour therapists hold faulty cognitive processing causal in the development of eating disorders, Eisler (1988, p.95) states that family therapists are usually “neutral to the question both of the origin and location of the disturbance”. Bi-directional influences between symptoms and familial functioning are acknowledged and addressed. The following quote describes bi-directional influences between anorectic symptoms and familial functioning: “the family unites in a concern for and protection of the child, thereby rewarding the symptoms” (Minuchin et al, 1978, p.61).

Both systemic therapy and CBT assume that the disorder serves a function for the individual. However, whilst in CBT the function would be a result of dysfunctional cognitive processing, Eisler states that in family therapy “it can be understood as an attempt...to resolve the stresses of normal development” (Eisler, 1988, p.97).

Eisler (1988) outlines the therapeutic process as follows: firstly, the therapist establishes relationships with each family member which enable him or her to experience the family’s interactional patterns and rules. He or she then reflects back the insight gained from this both directly and by adjusting his or her interactional style. The family’s usual patterns of interaction will be ‘blocked’ which encourages them to explore new interactional styles. As Minuchin et al (1978, p.21) state, “when significant family interactional patterns are changed, significant changes in the symptoms of psychosomatic illness also occur”.

**Systemic therapy for anorexia**

Minuchin, Rosman and Baker (1978) proposed an account of anorexia, the influence of which is evident in the frequency with which it is referenced (e.g. Russell et al, 1987; Eisler, 1988; Bryant-Waugh & Lask, 1995). They describe characteristics of the “highly enmeshed...anorectic system” as one which places “prime importance to proximity in interpersonal contact. Loyalty and protection take precedence over autonomy and self-realisation”. Children learn that others’ needs are more important than their own, which leads to “obsessive concern for perfectionism” and “increased
dependency on parental approval” (all quotes, Minuchin et al, 1978, p.59). Parents are over-protective and over-involved in their attendance to the child’s needs. Conflict avoidance is emphasised, and interactional patterns are inflexible. Bryant-Waugh & Lask (1995, p.18) outline the association between this rigidity and the maintenance of anorexia as follows: “anorexia nervosa provides a respite for the family which, rather than negotiating change, utilizes and supports the symptom to maintain the status quo”.

Minuchin et al (1978) relate the adolescent onset of anorexia to sexual development, the imminence of leaving home and parents’ consideration of their own adolescences. They state that competition between family and peer group induces attempts to change the family system, yet these attempts are ineffective and actually maintain enmeshment. Eisler (1988) acknowledges that anorectics are not unique in experiencing these developmental changes and cannot explain why anorexia is the reaction of a minority. In accordance with Minuchin et al, he advocates addressing the need for independence in therapy by uniting the parental subsystem. This is argued to enhance perceptions of separateness from parents, thereby enabling the exercise of independence in alternative, more adaptive, aspects of functioning than controlling food intake.

During treatment, Minuchin et al aim to promote “the growth of a system that encourages the freedom to individuate while preserving the connectedness of belonging” (Minuchin et al, 1978, p.91). However, by considering familial, academic and occupational functioning and extra-familial relationships as one outcome measure, their own data fail to emphasise this. Eating patterns constitute another outcome measure and an overall success rate of 86% is reported in the treatment of 50, predominantly adolescent (median age 14.5 years), anorectics and their families. In contrast to the other studies reviewed, which involved exclusively female samples, 6 participants in this study were male. Treatment was conducted by 16 therapists in weekly sessions and lasted between 2 and 16 months. Treatment goals and methods were adapted according to individuals’ needs. Although this may reflect common clinical practice, it is problematic when evaluating therapy.
Minuchin et al's outcome criteria are questionable as they do not state how they rated eating patterns as 'normal' or adjustment in familial, academic and occupational functioning, and extra-familial relationships as 'satisfactory'. There is also no comparison between other treatments or a waiting-list condition. Despite these weaknesses, the drop-out rate of only three families suggests that the treatment was acceptable to participants, and the follow-up period of between 18 months and 7 years is good. The authors suggest that the young age of participants and short duration of illness prior to treatment (range 1.5 - 36 months) contributed to their success.

Russell, Szmukler, Dare and Eisler (1987) conducted a controlled evaluation of family and individual supportive therapy for anorexia, examining differences according to age at onset and duration of illness prior to treatment. Their sample consisted of 57 anorectics who met DSM-III-R criteria for diagnosis, had a mean average body weight of 69.6% and a mean duration of illness of 3.8 years. Participants' mean age was 21.8 years. Symptom severity made hospitalisation necessary prior to psychological intervention; when and how participants were recruited is not reported. Treatment allocation was random. The individual therapy "was supportive, educational, and problem-centred, with elements of cognitive, interpretative, and strategic therapies" (Russell et al, 1987, p.1049). The mean duration of hospitalisation for those allocated to individual therapy was longer than for those allocated to family therapy. There were no other differences between the two groups.

Each therapist conducted both therapies and no significant differences were observed according to therapist. Results across treatments at one-year follow-up were disappointing; ratings of body weight and menstrual function were poor for 61% of the sample. Participants whose illness began before age 19 and had endured for less than three years demonstrated greater improvements from family therapy and greater attrition from individual therapy. Conversely, those whose illness began at or after age 19 improved more with individual therapy and were more likely to drop out from family therapy. There were no differences between the therapies among participants whose illness began before age 19 and had endured for more than three years. The
authors relate the observed differences to age differences, those with later onset of symptoms seem likely to be further removed from parental influences and therefore less likely to perceive the value of family therapy.

Treatments were not matched according to number of sessions as, when weight decreased, extra sessions were offered but attendance at these additional sessions was harder for families than for individuals. The differing effects across treatments suggests that there was no simple relationship between number of sessions and treatment outcome. Although the overall sample size appears adequate, allocation to three subgroups resulted in small groups for statistical analysis. The study raises a number of issues which require further research, including: a higher attrition rate prior to treatment among those offered family therapy; the influence of hospitalisation upon subsequent therapy, particularly the impact on family therapy of hospitalisation separating anorectics from their parents; the impact of family therapy upon other family members; and, the possibility of influences coming from family members not living within the household.

A five year follow-up of this sample was conducted by Eisler, Dare, Russell, Szmukler, le Grange and Dodge (1997) and demonstrated the same differences in treatment effectiveness according to age at onset of symptoms and illness duration. Due to differing sample sizes for follow-up, the authors place less emphasis on the effectiveness of individual therapy for later onset anorexia but express confidence in family therapy as “the treatment of choice in adolescent patients with anorexia” (Eisler et al, 1997, p.1029). However, their difficulty in obtaining complete follow-up data for all participants and reliance in some case on data from informants must be considered. Hsu (1980) notes that anorectics’ denial of difficulties renders data obtained via informants unreliable.

In summary, the evidence reviewed demonstrates that family therapy can be an effective treatment for anorexia. Success rates have been higher with adolescent samples, possibly because adults are further removed from familial influences (Russell
et al, 1987). As with the evidence reviewed in relation to CBT for bulimia, treatment success rates are relatively low.

**Systemic therapy for bulimia**

There has been less research regarding systemic therapy for bulimia than for anorexia. Dodge, Hodes, Eisler and Dare (1995) review the evidence concerning adult bulimics and note small samples and mixed results. Russell et al's (1987) controlled trial of individual supportive therapy and family therapy described above included a subgroup of 23 bulimic participants, all of whom met DSM-III-R criteria for diagnosis. As with the anorectic sample, hospital admission was necessary prior to commencing psychological treatment which demonstrates the severity of symptoms. Mean age at entry into treatment was 24.0 years and the mean duration of illness prior to treatment was 4.9 years. Results were poor across individual and family therapy; body weight and menstrual function were rated as poor in 78% of the sample. Overall outcome did not differ significantly between family and individual supportive therapy but a measure of mental state favoured individual therapy. There was a non-significant trend in drop-out rates with more bulimic than anorectic participants terminating therapy early. This contrasts with the report that anorectic patients are more difficult to engage in therapy as they deny their difficulties (Vaz-Leal & Salcedo-Salcedo, 1995). Eisler et al's (1997) five year follow-up again demonstrated no significant differences between treatments.

As family therapy has been relatively effective with adolescent anorectics (Russell et al, 1987; Eisler et al, 1997), Dodge et al (1995) investigated family therapy for 8 adolescent bulimics. Although recruitment from referrals to a Child and Adolescent eating disorders service would seem to produce a representative sample, one participant did not meet DSM-III-R criteria for bulimia. Participants' average age was 16 years 5 months and average onset of symptoms 14 years 4 months. The authors report "considerable variation in the severity of bulimic behaviours and attitudes" (Dodge et al, 1995, p.65) and histories of anorexia, self-harm and substance misuse but do not describe individual profiles in detail.
Treatment was adapted from work conducted with anorectics and, with the exception of one case which lasted longer, lasted between 1 and 8 months with a maximum of 10 sessions. Significant reductions in bingeing, vomiting and laxative use were reported. Family functioning altered, with “less discord, greater confiding… and … an increase in independence” (Dodge et al, 1995, p.71). Decreased but continuing self-harm and distortion in eating attitudes is also reported. It is possible that outcome was enhanced by the young age of participants and short duration of symptoms prior to treatment (Minuchin et al, 1978).

Unfortunately, the study does not address questions of directionality, whether changes in familial functioning were a precursor or a consequence of attitude or behaviour change. This would be interesting to address in future research. Although the study suggests that family therapy can benefit adolescent bulimics, results must be interpreted with caution due to the small sample size, poor inclusion criteria, absence of a control group and brief follow-up - some cases were followed up in significantly less than one year.

In summary, Russell et al’s (1987) failure to support family therapy as a treatment for bulimia may be related to the relatively older age of participants. The comparative success of Dodge et al (1995) might reflect the same bias as reported in conjunction with anorexia (Russell et al, 1987), i.e. that family therapy is more effective with younger participants and individual therapy more effective with older participants.

Conclusions

The evidence reviewed has supported the reports of Arnow (1999) and Bryant-Waugh and Lask (1995) that treatment outcome for anorexia and bulimia is poor. Studies have demonstrated that CBT can be relatively effective with female adult bulimics and family therapy relatively effective with female adolescent anorectics. Family therapy has demonstrated some success with adolescent bulimics. Whilst family therapy has
demonstrated lower success rates with adults, the effectiveness of CBT for female anorectics and adolescent bulimics has not been established.

The importance of increasing treatment effectiveness is evident in Russell et al's (1987) statement that the incidence of anorexia is rising as this will increase pressure for effective treatments. Each of the therapies reviewed here has the benefit of being relatively brief.

The proportions of patients remaining symptomatic following treatment demonstrates the need to continue developing effective treatments. Having found IPT, psychodynamic therapy and medication ineffective following unsuccessful CBT, Mitchell, Raymond and Specker (1993) and Wilson (1996) suggest offering more intensive treatment. Alternatively, eclectic treatment as implemented by Russell et al (1987) may prove effective, but to maximise effectiveness and efficiency delineation of which therapeutic ingredients are active will be required.

The studies reviewed suggest that it may be useful to further develop and investigate alternative individual therapies. Although IPT has been effective in the treatment of bulimia, it does not appear to have been used with anorectics. Within this group, the effectiveness of family therapy for adolescents suggests that the focus on interpersonal functioning may be beneficial. In addition, by considering general rather than specifically familial interpersonal functioning, IPT may be more accessible to adults than family therapy, and therefore more effective. This would be consistent with IPT’s advantage over family therapy with adult bulimics (Russell et al, 1987).

It is also important to consider different populations and categories of eating disorder, including Binge-Eating Disorder and ‘Eating Disorder Not Otherwise Specified’. Only one study reviewed here (Minuchin et al, 1978) included male participants but did not discuss treatment outcome according to gender. In addition, as Bryant-Waugh and Lask (1995) note that the incidence of anorexia varies across cultures and professions, these variables should be related to treatment outcome. In relation to the different categories of eating disorders, there appear to be some similarities across treatment
outcome, e.g. family therapy appears to be more effective with anorectic and bulimic adolescents than adults, but it would be poor practice to assume that these results will generalise to other disorders.

Specifically in relation to systemic therapy, research has focused on the traditional nuclear family and, although the influence of grandparents may be considered (Minuchin et al, 1978), the possibility of differences for those developing in different family constellations has not been addressed. There may be additional or alternative issues which require attention in, for example, single-parent families or families with step-parents.

Researchers appear to be emphasising the role of outcome predictors. These may improve treatment effectiveness by informing treatment planning. Fairburn et al (1995) report a significant relationship between paternal and premorbid obesity and poor outcome in bulimic women. Keel, Mitchell, Miller, Davis and Crow (1999) identify poor prognosis among bulimic women with a history of substance misuse. Vaz-Leal & Salcedo-Salcedo (1995, p.98) relate “lack of collaboration between family members and low motivation for change...vomiting, previous therapy and high expressed emotion” to poor compliance or prognosis within family therapy for anorexia. It is noteworthy that none of these variables appear exclusively relevant to family therapy. Conversely, Eisler et al (1997) report no relationship between expressed emotion and treatment outcome in their study of anorexia, thereby demonstrating the need for further research.
References


People with Learning Disabilities Essay

What is the impact of others' expectations on the communicative abilities of people with learning disabilities and how might a clinical psychologist work with these issues?

June 2000
Year 1
What is the impact of others' expectations on the communicative abilities of people with learning disabilities and how might a clinical psychologist work with these issues?

Introduction - why is it important to address communication?

“Communication is the most complex of all human behaviours and is fundamental to an individual’s experience of relationships, choice, assertion, control and emotional and self-expression. It enables an individual to develop personal identity and self-esteem, build relationships and exert a measure of control over their life” (Thurman, 1997, p.111).

Communication skills would seem to enable individuals to engage in a range of intra- and inter-personal activities. It is important to note that communication does not require verbal skills; individuals might use signs, symbols, gestures or behaviour to convey messages. Communication ability also appears to be important in making judgements regarding the self and others, particularly those with a learning disability:

“Our communication and language abilities are basic to how we define ourselves, and to how we perceive and evaluate others” (Warren & Yoder, 1997, p.379).

“Linguistic skills distinguish individuals who are gifted intellectually from those who are average intellectually and those with mental retardation more consistently than do other cognitive or social abilities” (Warren & Yoder, 1997, p.379).

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1 The differing terminology evident within the literature, i.e., mental retardation, mental handicap, intellectual disability and learning disability, will be treated as synonymous for the purposes of this essay, although the term learning disabilities will be favoured, in accordance with UK legislation.
This emphasis is not apparent in the American Association on Mental Retardation’s (AAMR) 1992 Definition of ‘Mental Retardation’ which focuses on intellectual ability:

“substantial limitations in present functioning. It is characterised by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, work…” (Hatton, 1998, p.22).

By only listing communication as one of several abilities which might be adversely affected by mental retardation, this does not emphasise the importance of communication for the range of experiences listed above.

Theories of language development have considered the relationship between language and cognitive development, and the role of others in language learning. Warren and Yoder (1997) provide an informative summary of the relationship between cognition and language, concluding that cognitive development usually precedes language development. However, they describe cases which demonstrate the development of linguistic skills independently of cognitive development. This implies that communication skills cannot be inferred from cognitive testing, and therefore require distinct consideration.

Remington (1998) describes models of language development, and rejects the nativist account in favour of an interactionist approach, which considers the contributions made by individuals and by their social environments. Price (1997) also advocates an interactional model, noting the importance of motivation to communicate and a responsive environment to reinforce communication. This emphasises the importance of considering the environments and social opportunities within which individuals function.
This essay will first describe the frequency and types of communication difficulties displayed by people with learning disabilities. Secondly, evidence regarding others' expectations and their importance will be explored, including the association between communication ability and challenging behaviour. Thirdly, the role of clinical psychology in addressing these issues will be considered, according to the skills outlined in the Management Advisory Service (MAS) report (Parry, 1989). These are assessment, analysis, diagnosis, treatment, evaluation, teaching and research. The relevance of each to working with the communicative needs of people with learning disabilities will be considered. Due to the greater understanding of children's communication and their differing needs, this essay will focus on adults with learning disabilities.

How many people with learning disabilities exhibit communication difficulties?

Blackwell, Hulbert, Bell, Elston, Morgan, Robertshaw and Thomas (1989) surveyed the communicative abilities of 536 learning disabled individuals in North East England. Staff rated their communication in social interaction and the expression of basic needs. 25% of the sample were observed to show 'severe' communication difficulty, defined as failure on over half of the items tested. These participants were contrasted with the highest scorers. There appeared to be an age effect, with the lowest scores achieved by those aged 19-24, and the highest scores from those aged 35-54, but this is disregarded due to its lack of statistical significance. The possibility of an age effect requires further investigation, as Rondal (1987) reviewed research which found that adults with learning disabilities demonstrate continued language learning beyond puberty. Individuals with concurrent physical disabilities demonstrated significantly reduced communication ability. Blackwell et al. suggest that this is partly attributable to their reduced social opportunities, thereby recognising the importance of others in communication development. Similarly, hospitalised individuals were found to be less effective communicators. Although causal explanations cannot be made from this analysis, research has described the reduced opportunities for communicating in institutions (Felce, Saxby, de Kock, Repp, Ager & Blunden, 1987, discussed later...
within this essay). However, the reasons for hospitalisation, not discussed within this paper, will also be important.

The authors state that gender was not related to communication ability, but suggest that women are more likely to use their social skills. They attribute the higher performance of female participants to a gender bias in part of the assessment, but do not explain this conclusion or consider alternative explanations. They do not separate the two, very distinct, areas of communication under investigation, which might have proved informative. For example, the expression of needs might be more strongly motivated than social interaction. Additionally, Blackwell et al. do not describe participants’ communication opportunities or staff characteristics such as profession, training, and degree of contact with clients, each of which would seem to have the potential to affect their ratings.

McLean, Brady and McLean (1996) investigated the communicative abilities of 211 individuals with severe mental retardation, defined as an IQ of between 20 and 40. They compared the abilities of children aged 7 to 12, and adults aged 25 to 35. As in Blackwell et al.’s study, ratings were completed by staff, but their professions are identified. The authors note that school personnel tended to complete children’s reports, and residential staff completed adults’, which might introduce bias in expectation differences. Ratings indicated that 59% of the sample used symbolic communication, 19% intentional non-verbal communication, and 21% no intentional communication. There were several differences from Blackwell et al.’s results. Firstly, secondary physical disabilities were not found to contribute to higher rates of communication difficulty. Secondly, there was no significant difference between residential status, although children were excluded from this analysis due to the small number in institutions. Thirdly, adults were significantly more likely to use symbolic communication, which appears consistent with the research reviewed by Rondal (1987). However, the authors also consider the possibility that adults who remain unable to acquire symbolic communication become reclassified as ‘profoundly’ learning disabled.
Increased rates of aggressive behaviour were recorded among individuals with more advanced communication ability. It is suggested that this might be due either to a lack of distinction in recording verbal versus physical aggression, or to increased frustration when communications are not acknowledged. It is disappointing that no measures were made of communication effectiveness. Lastly, the authors note that researchers should ideally conduct direct observations of communication, rather than relying on others' ratings, but note that this is time-consuming. They conclude that their results demonstrate the range of communicative ability within this subgroup of the learning disabled population, which cannot be predicted from their intellectual status alone.

Van der Gaag and Dormandy (1993) cite higher prevalence rates for communication difficulty in the learning disabled population, between 66 and 89%. This variability might in part be attributable to methodological issues such as sample selection and method of communication assessment. However, whilst a significant proportion of people with learning disabilities exhibit communication difficulties, these cannot be predicted. This demonstrates the importance of independent consideration of communicative ability. Current research findings do not enable conclusions to be drawn regarding the relationship between communication difficulty and age, gender, physical disability and residential status.

How are communication difficulties manifest within the learning disabled population?

As has already been implied, communication difficulties can take different forms. Blackwell et al.'s (1989) study identified people with learning disabilities who were unable to express their basic needs or engage in social interaction. McLean et al.'s (1996) study investigated the use of symbolic and intentional non-verbal communication, also identifying a group who did not use intentional communication. These clients represent the opposite end of the continuum to the minorities cited in the Van der Gaag and Dormandy (1993) statistics who did not demonstrate communication difficulty. When considering communication difficulties, researchers have tended to focus on verbal communication. Difficulties in the use of augmentative
and alternative forms of communication, other than facilitated communication (e.g. Hastings, 1996), have received much less attention.

Bull (1995) outlines research findings pertaining to communication difficulties, although these are not restricted to people with learning disabilities. He outlines studies which report greater variability in responses with changes in the structure and wording of questions, and the setting within which they are asked. It has been reported that acquiescence increases with decreased IQ. The tendency to comply with leading or suggestive questions is increased if it is clear that the interviewer is already knowledgeable about the events under discussion. Increased confabulation has been reported when people are under pressure and during cognitive interviews; as with acquiescence, this might be a result of low self-esteem and a desire to please the interviewer. The use of pictures and open-ended questions have been found to elicit more accurate information. Although Bull's review is tailored to interviews within legal contexts, these principles and the need for staff training in order to address these tendencies appear equally relevant to other forms of interview with this client group.

Adhering to the interactionist approach to the study of language, Leudar (1997) analysed the interactions of people with learning disabilities by conducting factor analyses comparing ratings of communication characteristics for people with and without learning disabilities. Unfortunately, the demand characteristics apparent in asking participants to complete questionnaires regarding both clients in their care and non-handicapped acquaintances are not considered. However, a large sample was obtained, with good matching of age and gender between the two groups. The learning disabled sample included people across the ability range. Results indicated that both groups generally acted according to the same conversational maxims, with a few exceptions. Within the maxim of quality, the 'evidentiality' clause was not apparent for people with learning disabilities; this was evident in their conversational partners requiring validation of statements, even when they were obviously true. In addition, a hostility factor was obtained for the interactions of learning disabled people; again this seems to be an interpretation made by conversational partners in the event of conflict or unwillingness to co-operate. This appears to reflect the power differential between
staff and clients, i.e. non-learning disabled individuals seem unlikely to rate their peers as hostile for not meeting a request. Drawing to mind the opening quote given by Thurman (1997), Leudar concludes that:

"communication environments for mentally handicapped people are systematically distorted and do not provide the same opportunities as those for average persons" (Leudar, 1997, p.296).

Keman and Sabsay (1997) conducted a participant observation study of the everyday conversations of adults with mild learning disabilities. Although the objectivity of this approach is questionable, and the report does not address the authors' previous contacts with people with learning disabilities, interesting insights into this group's experiences are achieved. Keman and Sabsay suggest that they might portray their learning disability through unusual communicative behaviours, evident either in qualities of their speech such as volume, quality of voice and use of grammar, or in their speech content, for example by contributing irrelevant or intimate details. They focus on two areas of communication - transmitting intended meaning and conduct within social interaction - which they hypothesise to be difficult for this population, although they do not explain how they reached this conclusion. Within the communication of meaning, the authors note that shared knowledge facilitates communication for this client group, such that communications become meaningful when related to the listener's existing knowledge of the speaker. One cannot help questioning the contribution of disempowerment in this phenomenon, i.e. that clients have not developed adequate skills because the carers with whom they most frequently interact have access to most areas of their lives. The authors report observing embarrassment when participants encountered difficulties in communicating meaning and others intervened or listeners demonstrated impatience or discomfort.

Within the management of social interaction, Keman and Sabsay observed restricted conversational topics, which are sometimes unusual or fanatical, and disruptions in turn-taking, evident in interruptions and an absence of attention to others, particularly
when conversations involved more than two people. Conversational partners were observed to display a range of reactions, including impatience, withdrawal, and ignoring or drawing attention to the inappropriate aspects of the interaction. The authors describe techniques employed by participants to enhance perceptions of their competence. These included procrastinating, speaking too loudly, using visual clues, pretending to understand, using humour to hide mistakes and discussing areas of knowledge and accomplishment. These strategies have the potential to complicate interpretation of clients' communication skills, as their use may not be obvious, and, as intended, could be very misleading. The range of situations described in which communication can be difficult, frustrating or embarrassing, and the resulting low self-esteem, indicates the extensive need for interventions to address communication.

What are others' expectations regarding the communicative ability of people with learning disabilities, and why are they important?

There is very little published research in this area. Hodgkinson (1998) conducted interviews with 12 staff from a range of professional backgrounds. They reported good understanding that clients do not need speech to communicate and might communicate through challenging behaviour, and identified social skills as crucial to acceptance in the community. Staff accepted that they held an important role in developing communication skills but did not feel sufficiently skilled to confidently perform this role. They requested further information regarding different disabilities, to include assistance in developing accurate expectations for individuals, and focused on individuals' skills such as vocabulary as targets for intervention. Although the sample size inhibits the generalisation of results, this study infers the importance of assessing staff's knowledge and opinions before effective interventions can be applied. A larger replication of this study could usefully examine differences between professions, and the effects of training.

Purcell, Morris and McConkey (1999) compared care staff's perceptions of 28 clients' communicative abilities to results obtained from the Communication Assessment Profile (CASP, Van der Gaag, 1988; see Van der Gaag & Dormandy, 1993, for an
evaluation of this and other assessment tools). They explain that staff perceptions are important through their:

"effect...on their interactions. If their assessment...is inaccurate or incomplete they may fail to make the necessary adjustments to the way they communicate so as to maximise their partner's ability to contribute to the dialogue" (Purcell et al., 1999, p.17).

Although staff comprised a self-selected sample, which can be assumed to introduce bias in their motivation and understanding of the importance of communication, they represented a range of roles, from managers to care assistants. That they chose the clients sampled might introduce another bias. Clients' cognitive abilities are not reported but it is stated that approximately half required aid with self-care, one third had mobility difficulties, and 40% exhibited 'behaviour problems'.

Staff were found to overestimate clients' abilities to comprehend spoken language, and did not report the full extent of hearing difficulties. Particular difficulties were noted in the identification of non-verbal and 'comment' communications. In accordance with Hodgkinson's (1998) results, staff attributed improved communication to internal, rather than external, changes. Beyond the conclusion that staff had unrealistic perceptions of clients' communicative abilities, these results raise two important issues. Firstly, it is likely that the staff who work regularly with clients have a communicative advantage over visiting speech and language therapists, and secondly, testing conditions are likely to impact negatively upon clients' abilities. This study therefore highlights the need for close liaison and co-operation between carers and outside professionals.

**Communication and challenging behaviour**

As suggested by McLean et al.'s (1996) results, communication is important in the field of challenging behaviour. Emerson, Toogood and Mansell (1987, in Russell, 1997, p.12) define challenging behaviour as:
"behaviour of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or delay access to and use of ordinary community facilities".

Chamberlain, Cheung Cheng and Jenner (1993) directly addressed the relationship between communication ability and challenging behaviour. They assessed the communicative abilities of 15 clients using Kiernan and Reid’s (1987) Pre-Verbal Communication Schedule. Clients were selected from earlier assessment reports, which had classified them as profound multiple learning disability, pre-verbal or verbal. The incorrect classification of two clients demonstrates the difficulty of providing accurate assessment of communication ability, as introduced following discussion of Purcell et al.’s (1999) results. Completion of the Problem Behaviour Checklist (PBC) enabled examination of the incidence of challenging behaviour according to communication status. The use of a non-parametric test (Mann-Whitney) reduced statistical power. Despite this, increased behaviour problems were recorded for those with reduced communicative ability. Unfortunately the PBC does not describe the severity or frequency of behaviours. Chamberlain et al. introduce the idea that challenging behaviour has a communicative function by discussing research which suggests that it receives more attention from staff.

Bott, Farmer and Rohde (1997) obtained equivalent results with a larger sample. They conducted a Chi square analysis on data pertaining to 3662 learning disabled individuals, rating speech output and understanding as “None, Basic Needs, or More than Basic Needs’. The incidences of eight behavioural disturbances (personal habits, self-injury, damaging, overactive, hitting, wandering, noise and attention-seeking) were found to significantly decrease with increasing communication ability. This effect was maintained when individuals with mild learning disabilities, autism or Down’s syndrome were excluded from analyses, so can be assumed to be independent of degree of disability and diagnosis. Although the study’s simplicity grants noteworthy
clarity, the authors cite the following problems: information regarding the type of communication difficulty, use of gesture or other non-verbal expression, and presence of medical problems was not available, and individual variation might have influenced the ratings. Additionally, parametric statistics would have increased statistical power, and operational definitions of the behaviour categories are not provided. The degree of challenge posed by these behaviours would seem to differ according to frequency, severity and context. The authors conclude that their results highlight the need for early multi-disciplinary speech and language therapy involvement before behavioural problems develop.

In a replication of earlier work by Warren and Mony (1971) which revealed that staff ignored the majority of appropriate behaviour, but responded to higher rates of inappropriate behaviour, Felce, Saxby, de Kock, Repp, Ager and Blunden (1987) investigated staff's responses to appropriate and inappropriate behaviour. They observed the communication environments of 90 learning disabled participants living in a range of residences, grouped according to their size. Age and behavioural functioning were matched but staffing ratios increased as the number of residents decreased, and the authors do not address the reasons behind placements. Results indicated that clients living in smaller homes, with increased staff ratios, received increased encouragement for appropriate communication. Within these residences, there was a differential indicating that staff were more likely to respond to appropriate rather than inappropriate behaviour. This also supports clients in the development and utilisation of appropriate behaviours. However, the authors acknowledge that there were other, non-controlled, differences between the residences, including training and roles undertaken by staff, service philosophy, physical environment, organisation and degree of autonomy.

How might a clinical psychologist work with communication issues?

The following discussion will be structured according to the roles outlined in the MAS report, although where there is substantial overlap, activities will receive simultaneous consideration.
Assessment, Analysis and Diagnosis

Bull (1995) lists techniques which facilitate accurate responding. These include not repeating questions, not jumping to conclusions, checking the interviewer’s and the interviewee’s understanding, and using either-or rather than yes-no questions, although he notes that limited choices can yield inaccurate responses. He also warns against ignoring apparently trivial information, as it cannot be assumed that important details will be presented as such. In line with his review of relevant research, interviewers must avoid leading people with learning disabilities into false agreements due to poor understanding or the power imbalance. Use of pictures and open-ended questions can boost accuracy. Where context is important, clients should be introduced to environments and procedures prior to interview. It would also seem profitable to analyse interview outcomes according to relevant research findings.

Price-Williams (1997) notes that diagnosis is complicated by reduced ability to describe internal processes, and advocates extending assessment until all alternatives can be excluded. He also suggests analysing indirect measures of clients’ internal worlds, such as guided imagery, to advance assessment and therapy beyond the limitations of direct questioning.

When assessing clients who present challenging behaviour, the association between challenging behaviour and deficient communication ability demands a thorough communication assessment, and subsequent intervention where needed. Functional analysis might demonstrate that clients display challenging behaviour when they are unable to understand what is expected of them, or cannot express their needs and desires. McGill and Toogood (1994) describe social contact as one of the primary motivators of challenging behaviour, and indeed research has shown that staff give higher rates of responding to such behaviour (Felce et al., 1987).
Treatment

Many of the principles discussed in relation to assessment and analysis also apply to treatment. Depending on the outcome of assessment, treatment with this client group may take various forms including therapy, behavioural interventions and direct communication skills training (see teaching, below). Leudar (1997) notes that communication problems can relate to emotional and/or social problems. This implies that therapy which addresses emotional and social difficulties might alleviate some communication difficulty. Clinical psychologists might meet this need either by providing direct therapeutic intervention, or by supervising others who undertake such work.

Price-Williams (1997) describes therapy cases in which emotional expression was problematic for learning disabled clients, all of whom were experiencing difficulties in interpersonal relationships or occupational functioning. He considers the potential communications underlying withdrawal, which requires clinicians to address the power differential and use appropriate means to engage individual clients according to their readiness, needs and interests. Echoing one of the interview hints offered by Bull (1995), Price-Williams reframes the notion of triviality and notes that analysis of such contributions enables clients to select material for discussion and, albeit sometimes indirectly but non-threateningly, express important issues. This transfer of skills demonstrates the potential for learning across contexts. The message throughout this chapter is that a clinical psychologist working with people with learning disabilities will benefit from conducting in-depth analyses of interactions, as important issues may not be presented as such, and might reveal themselves in quite subtle ways.

Fraser (1997) advocates facilitating communication by reducing formality and increasing enjoyment. He suggests interacting in different contexts and modalities, whilst communicating regularly, consistently, and assuming intentionality in all behaviour. Like Bull (1995), Fraser (1997, p.184) states that “the onus is on [the interviewer] to ensure you are understood”. Although these requirements can appear to demand precious time when working within the NHS, they might be essential to
establishing and maintaining engagement with some clients, and facilitate a thorough understanding of interests and needs prior to and throughout treatment.

Interventions for challenging behaviour will frequently require intervention for communication difficulty. A full review of techniques in this area is beyond the scope of this essay. However, when assessment demonstrates that communication skills are inadequate, a thorough speech and language therapy assessment can help determine the individual’s ability. Intervention might then involve assisting staff to adjust their interactions accordingly. McGill (1993, p.17) argues that interventions should offer:

“support and assistance...high rates of social contact...increasing the skills, especially communication skills, and abilities of people to exercise choice and control in their own lives”.

Slightly differently, McGill and Toogood (1994) describe social contact as one of the primary motivators of challenging behaviour, and research has shown that staff might give higher rates of responding to such behaviour (Felce et al., 1987). Where thorough assessment identifies this function, it might be addressed by developing alternative means to meet the need for social contact.

Teaching

Education and training can be delivered to different audiences, which might include clients and carers. MacDonald and Gillette (1986) discuss communication enhancement throughout interaction and language development, by working with parents and professionals to optimise conditions for the language learner. They focus on ‘progressive matching’, which consists of adults matching their interaction and communication styles to those of learners, then modelling slightly more advanced skills, encouraging learners to progress to that stage. They suggest engaging learners in pleasurable, demand-free activities before progressing to relaxed turn-taking, still encouraging learners to remain in the interaction. Once learners are engaged, progressive matching can be employed to promote skill development, whilst
conversation focuses on the learners' interests and experiences, gradually progressing to more advanced topics and styles.

Strengths of this model include its emphasis on interaction skills as a prerequisite for communication development, its focus on communicative dyads rather than individuals, and its use of activities and topics of interest to learners. However, the authors admit that their research has focused on children. Although the approach appears to offer promising techniques by which to facilitate engagement, interaction and communication, it requires research regarding its applicability to, particularly non-verbal, adults with learning disabilities. In particular, the descriptions and effects of parents' speech with children with learning disabilities would benefit from replication in the adult population. This approach could be implemented directly, thereby training clients, or indirectly through training carers.

There is a growing emphasis on the use of 'total communication' environments in speech and language therapy intervention (Warren & Yoder, 1997). This involves simultaneous speech and gestural or symbolic communication and is thought more beneficial to overall communication development than sign or symbolic language in isolation. This style of approach has implications for everyone interacting with people with learning disabilities. Accordingly, Forshaw and Richards (1997) describe the establishment of total communication within a learning disabilities service. This involved providing total communication and Makaton training to direct care and managerial staff, the multi-disciplinary team and advocacy agencies. Psychologists could clearly benefit the development and application of such training.

Evaluation and Research

There are various ways in which clinical psychologists evaluate treatments and services. Direct treatment evaluation frequently involves comparing current functioning to baseline data, and demonstrates whether treatments meet their goals. Clinical governance emphasises the importance of clinical audit and evidence-based practice. Each of these activities is enhanced by the application of effective research skills.
Warren and Yoder (1997, p.391) state that within the field of communication in learning disabilities there is "insufficient quality and quantity of research, insufficient research funding [and] ineffective transfer of research findings to practice". Price (1997) also describes the paucity of research in this field and notes the importance of considering sample characteristics, methodology and context.

Staff training is receiving increasing attention in research. The following studies demonstrate the potential for psychologists to conduct research, and assist the implementation of results from studies conducted by others. Brown (1999) reports from experience and published research that information gained in training is not always consistently incorporated into ongoing care, so employed continuing feedback to boost adherence. Before and after intervention, the incidence of challenging behaviour and staff's language complexity and use of augmentative communication were recorded. Brown notes that, in line with the results reported above from Purcell et al. (1999), staff over-estimated the client's ability to understand spoken language. Initial intervention involved an educational workshop regarding the general conversation strengths and needs of learning disabled adults and the specific needs of the client, and set goals for improved communication with her. However, a further combination of modelling, prompting, positive reinforcement, feedback and ad hoc reviews were required to produce improvements in each of the areas assessed. Although results from case studies cannot be generalised to other contexts and no causality can be assumed, this study draws together the diverse strands of this essay: unrealistic communication expectations, excessively complicated speech with insufficient gestures, elevated challenging behaviour, and a need for intensive staff training.

Bartlett and Bunning (1997) investigated interactions between 7 clients and their keyworkers in two conditions, analysing the keyworkers' use of information-carrying words. They found that staff simplified their language, making it clearer and more direct, when they were looking at pictures with clients as compared to during unstructured time. Although the sample size is limited, this study suggests that total
communication training will help carers adjust their verbal communication, as signs and gestures would seem to provide a similar cue to the need to adjust their speech as that provided by the pictures. The increased reciprocity appeared to help carers monitor the clients' abilities. The authors acknowledge that they focused exclusively on information-carrying words, and did not assess non-verbal communication, but do not address the effects of the unnatural testing situations.

Suphi (1994) describes an intervention designed to assist clients make choices. Results demonstrated greater improvements when more than one client was involved in the programme. Again the sample size was limited, but this provides support for the development of total communication systems throughout services rather than targeting specific individuals. This style of approach would also seem less stigmatising for the individuals concerned.

Conclusions

A significant proportion of people with learning disabilities demonstrate a variety of communication needs, ranging from total inability to communicate to quite discrete weaknesses in conducting social interactions. Difficulties may present across settings or within specific contexts and are present across the ability range. Their assessment is complicated by the use of idiosyncratic compensatory strategies. Consequences of communication difficulty include embarrassment, low self-esteem, frustration, disempowerment, and challenging behaviour.

Others' reactions to communication difficulties are varied, and include highlighting or ignoring the difficulty, becoming impatient or withdrawing. Although there is very little research in this area, there appears to be a tendency for staff working with people with learning disabilities to over-estimate clients' ability to comprehend spoken language. This seems likely to inhibit the use of sufficiently simple, direct speech with simultaneous augmentative communication.
It therefore appears clear that communication must be considered throughout work with the learning disabled population. The specific roles of clinical psychologists can be summarised with reference to the roles outlined in the MAS report (Parry, 1989). Assessment and diagnosis require careful planning to ensure that information received is reliable; this might require increased time as compared to working with other client groups. Throughout assessment and treatment, there appears to be an exaggerated need for careful analysis and interpretation of all communications made by clients.

There is an intensive need for staff training, within which the application of research findings should boost the implementation of acquired skills. Lastly, the need for adequate evaluation of clients' abilities, treatments and services highlight the considerable inadequacies in our knowledge base, thereby demonstrating the need for further research in all areas reviewed. There is a particular need for large-scale controlled studies evaluating the interventions employed to enhance communication ability. Research skills can then facilitate the effective application of results to clinical practice.
References


Children, Adolescents and Families Essay

Psychiatric classification is irrelevant to the understanding and treatment of mental health problems in childhood and adolescence. Discuss.

Dec 2000
Year 2
Psychiatric classification is irrelevant to the understanding and treatment of mental health problems in childhood and adolescence. Discuss.

Overview of classification and its functions

There are many contentious issues regarding the utility of psychiatric classification. This debate is not new, and is not specific to child psychology. An article published this year regarding the use of diagnoses and formulations in court reports (Pilgrim, 2000) sparked a debate covering such varied issues as inter-rater reliability of psychological formulations (Scragg, 2000), diagnostic language and the reification of disorders (Cox, 2000) and the acceptability of diagnoses to clients (Marziller, 2000). It will be the aim of this essay to describe and evaluate current classification systems, provide an overview of some of the issues surrounding classification and contemplate the psychologist’s role in classification. Throughout, factors which are particularly relevant to working with children and adolescents will be highlighted.

It is important to recognise that classification is not just a tool of psychiatry and psychology but is embedded in contemporaneous attitudes within society, which it also informs. Its popularity blossomed over the first half of the twentieth century, culminating in the first publications of the International Statistical Classification of Diseases, Injuries and Causes of Death (ICD) by the World Health Organisation in 1948 and the Diagnostic and Statistical Manual (DSM) by the American Psychiatric Association in 1952 (Phares, 1992). Before this time, many classification techniques were in circulation (Reid & Wise, 1995), but none had been used either nationally or world-wide. It was therefore not possible to compare diagnoses made at different medical centres or in different research projects. DSM and ICD have attempted to address this shortcoming. Phares (1992) reports that the popularity of classification waned during the 1950s and 1960s amidst arguments that it was dehumanising and ignored individual variation. At approximately the same time, Goffman (1961; 1963) described the stigma suffered by those labelled as psychiatric patients. These books have an enduring influence on those interested in the ethics of classification. Since their
initial publications, ICD and DSM have each been revised several times but both they and classification per se remain controversial.

To assess the relevance of classification, it is important to consider the functions it could serve. Carr (1999) argues that it should facilitate communication among professionals, provide a means of organising information and research, and inform epidemiology and planning. Sonuga-Barke (1998) adds that it should identify who requires treatment, and of what nature. Clark, Watson and Reynolds (1995, p.123) describe the reciprocal relationship between classification and research as “an unintended straitjacket”, because researchers restrict themselves to participants who meet DSM criteria. This then means that their results can only be used reliably by clinicians working with clients who meet such criteria. When analysing research, it is important to consider how clinical cases are defined, and how this information is gathered. Clark et al also state that the most important criteria for a classification system to achieve is the prediction of outcome and treatment response, thereby enabling the allocation of individuals who need treatment to the most effective and efficient interventions. Despite the increasing emphasis on evidence-based practice in the NHS, it will become apparent that this goal is far from being achieved.

**Description of current categorical systems of classification**

The current version of DSM (DSM-IV) was published in 1994. Since DSM-I, revisions have included such changes as: reducing dependency upon psychodynamic concepts and explanations and an increased reliance on measurable, observable criteria; changes of nomenclature; omission and addition of individual disorders; and the introduction of five axes upon which to record information (clinical syndromes, personality disorders and mental retardation, medical conditions, psychosocial and environmental problems and assessment of functioning). Disorders are organised in groups, the most relevant of which to this essay is ‘Disorders usually first diagnosed in infancy, childhood or adolescence’. This includes mental retardation and disorders of learning, pervasive developmental disorders, attention-deficit and disruptive behaviour disorders, feeding and eating disorders, tic disorders, elimination and other disorders.
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(Reid and Wise, 1995). For any condition to be diagnosed, clients must meet a range of criteria describing the problem’s type, frequency, severity and duration. Criteria are given for differentiating between conditions which might present similarly. For some disorders, it is necessary to identify the relevant subtype, this might relate to the nature or context of presentation or age at onset. When clients do not meet the essential or required number of criteria, a diagnosis can be made, suffixed ‘Not otherwise specified’ (NOS).

Clark et al (1995) state that, because DSM-IV uses combinations of equally weighted criteria to reach a diagnosis, individuals receiving the same diagnosis can demonstrate contrasting patterns of symptoms, which are only equivalent in the number of symptoms displayed. This within-category heterogeneity appears antithetic to the categorical approach adopted by DSM and ICD, which assumes that disorders are discrete entities which differ from normal by their nature (Sonuga-Barke, 1998). This has major implications for the use of classification as a communication aid, as it cannot be assumed that two individuals with the same diagnosis will display the same symptoms. Additionally, by placing individuals with differing constellations of symptoms into one category, there is a danger that the possibility of different causal explanations and outcomes according to different presentations will be overlooked. In his discussion of the different philosophical approaches underlying different methods and attitudes towards categorising psychopathology, Sonuga-Barke notes that each of the classification systems proposed has merely been constructed to represent an, as yet unknown, underlying reality. Alternatives to categorical classification will be considered later in the essay.

The development of DSM-IV received considerable attention within academic journals. Clark et al (1995) noted the inherent bias in establishing improvements using research conducted according to criteria laid out in earlier versions of DSM, as this assumes that the basic structure and format of the classification system are appropriate. Revisions also reduce available knowledge, one of the criteria stated as a function of classification, as the application of data from research using earlier editions becomes questionable. Despite the overwhelming emphasis on DSM in the literature, Frances,
Widiger and Pincus (1989) report that its latest revision was made primarily to coincide with the publication of ICD-10 and co-ordinate the two systems. They note that when revisions are made, research and clinical practice are disrupted, and there is a danger that diagnosis appears whimsical. However, this might emphasise the fact that diagnoses are constructed and prevent their reification. Frances et al (1989) describe the process of change using systematic literature reviews regarding validity, reliability, antecedent, concurrent and predictor variables, but note that there is little consensus on these last factors. As an example, the earlier change, rejecting psychodynamic concepts in favour of observable behavioural features, was partly a reaction to data regarding the poor reliability of diagnosis. The impact on other diagnoses and the system’s ease of use were also considered before making changes.

Volkmar and Schwab-Stone (1996) compare and contrast DSM-IV and ICD-10. They note that whilst DSM-IV is designed for use by clinicians and researchers, ICD-10 provides different systems for each. This might explain the more widespread use of DSM in clinical research, as direct comparisons and applications can be made between research and practice. Volkmar and Schwab-Stone note that ICD-10 addresses comorbidity (to be discussed later in the essay) by incorporating some combination categories. These are absent in DSM-IV. Additionally, DSM-IV involves a ‘bottom-up’ approach where diagnoses are obtained according to the symptoms presented, but ICD-10 uses a ‘top-down’ approach, requiring a ‘best-fit’ diagnosis. Between the two systems then, there is a balance between representing the individual’s range of symptoms and parsimony. On an organisational level, it is noted that ICD-10 has more classes for childhood disorders - mental retardation, psychological, and emotional or behavioural - rather than DSM’s cluster of disorders according to their age of presentation. This would seem advantageous for those working with children and adolescents. Volkmar and Schwab-Stone conclude that the similarities between the two systems outweigh their, predominantly pragmatic, differences but state that neither awards development or stability across time sufficient attention. This is obviously crucially important in the classification of problems in childhood and adolescence.
Strengths of current systems of classification

It has been noted that classification is controversial, and many authors have expressed a range of criticisms of the DSM and ICD systems. To consider their strengths first, Hoghughii (1992) praises their coverage, stating that the range of conditions described enables detailed differentiation of childhood problems. He also notes that good reliability data have been achieved for some conditions, the systems have been usefully applied to the study of cross-cultural differences and have provided a common vocabulary through which children’s difficulties can be understood and explored. This last factor is one of the functions of classification cited above. Carr (1999) adds that the multiaxial framework is advantageous, because it enables the inclusion of relevant influences on mental health, such as social adversity, and provides scales for assessing intellectual and social functioning. By enabling multi-axial diagnoses, DSM provides a comprehensive assessment of an individual’s difficulties. It has both provided a basis for organising research and been informed itself by research (Clark et al., 1995). This should mean that its evidence base is strong and, because it is atheoretical, is not limited to clinicians working within a particular model, but can be readily understood and applied by a range of professionals. However, this last point is contentious. Sonuga-Barke (1998) relates DSM-IV to the medical model, with its assumptions of categories as previously outlined. Differing conceptualisations of disorders are reflected in the different bases for categorisation within DSM-IV; whilst most disorders are categorised according to behavioural observations, some are categorised by organic or psychosocial factors, e.g. brain damage or exposure to toxic agents (Phares, 1992).

Weaknesses of current systems of classification

Comorbidity

The frequency with which comorbid conditions are diagnosed according to DSM criteria has frequently been cited as a major problem with the classification system. It is much harder to find data regarding ICD. Anderson, Williams, McGee and Silva (1987)
investigated the prevalence of DSM-III disorders in a community sample of 792 11-year old children. Using their own, non-standardised, modifications of the Diagnostic Interview Schedule for Children (DISC) and Rutter Child Scales A and B for recording information from parents and teachers, they obtained an overall disorder prevalence of 17.6%. As the study was longitudinal, the authors were able to report that 7.3% of the sample displayed a pervasive disorder, as assessed by earlier completion of the Rutter scales and corroborated by parents' reports. Of those who met criteria for DSM-III diagnoses, 55% met criteria for two or more conditions. The authors note that their prevalence figures are high, and question whether parents over-reported their difficulties in questionnaires. It is also noted that help had been sought more frequently for those with high-profile and/or comorbid conditions. The reasons for this and implications for clinical practice and research require further research. It is possible that parents minimise isolated difficulties, attributing them to situational or developmental factors, but become overwhelmed when they have to manage multiple conditions.

Kashani et al (1987) conducted a similar study with 150 adolescents, aged 14-16. According to diagnostic interviews, 41.3% of the sample met criteria for at least one DSM-III diagnosis. However, this figure dropped to a less shocking 18.7% (which is readily comparable to that found by Anderson et al) when the authors added their own, poorly defined, criteria regarding impaired functioning and need for treatment. Of these 28 participants, it is noted that only 7 had one diagnosis and the mean number of diagnoses was 2.4. Kashani et al note that whilst the reliability of self-report data increased with age, that of data obtained from parents decreased. This has implications for clinical practice and the interpretation of data from other research studies.

McGee, Feehan, Williams, Partridge, Silva and Kelly (1990) obtained a higher prevalence figure in their community sample of 943 adolescents aged 15. 25.9% of girls and 18.2% of males met criteria for at least one DSM-III diagnosis according to an abbreviated form of the DISC, a parent-completed questionnaire and a measure of social competence. It is not possible to ascertain the influence of different methodologies, interview versus questionnaire, for identifying disorder. Of those who
met criteria for diagnosis, only a quarter met criteria for multiple diagnoses, which contrasts quite markedly with the previous studies. Comorbidity was noted to be more common among adolescents suffering from depression, and less common with conduct and oppositional disorder. Approximately 10% of the sample suffered from a condition which was corroborated by parental report, this was not an artefact of disorder severity but did appear to be related to poor social competence, maternal depression and perceived lack of social support. In light of the previous study, it is not clear how much emphasis should be given to parental data confirming diagnosis.

McConaughy and Achenbach (1994) investigated comorbidity with 2,705 children and adolescents aged 4 to 18, comparing community and clinical samples. Parent, child and teacher ratings identified a prevalence of between 4.6 and 7.7% in the community sample and between 11.5 and 41.6% in the clinical sample, using DSM-III diagnoses and empirically based syndromes, as assessed by the Child Behaviour Checklist (CBCL). Their use of a borderline clinical cut-off to distinguish between cases contrasts the more rigid criteria used by Kashani et al. The parent-completed CBCL identified comorbidity rates of between 10.5 and 30.2% in the community sample, and 21.5 and 51.9% in the clinical sample. McConaughy and Achenbach relate this result to referrers being more likely to refer those with multiple problems, but it cannot be assumed that referrers are aware of each condition. This is an area which would benefit from further research. In contrast to McGee et al, the obtained comorbidity rates were higher for aggressive and delinquent behaviour disorders, and lower for somatic complaints. It seems possible that this last result might be confounded by the existence of bona fide medical conditions. The authors note the importance of examining bi-directional comorbidity, rather than just starting with one condition. They conclude that, since extensive research is conducted on participants with isolated diagnoses, research needs to involve participants with comorbid conditions and assess risk and protective factors, disorder outcome and treatment response.

From this review, it is apparent that accurate estimates of comorbidity are extremely difficult to obtain. In these studies, there are differences in the age of participants, setting (USA and New Zealand), methodologies and the cut-off points used to identify
disorders. Now that DSM-III has been superseded by DSM-IV, the generalisability of these data has become even more questionable. Although not borne out in this research, Clark et al (1995) state that comorbidity is systematic according to diagnosis, and requires its own research to address questions including whether apparent comorbidity is the expression of a single disorder, the consequence of a common vulnerability or the unrelated expression of two disorders. Such questions obviously have clear implications for treatment. Using the example of eating disorders, they wonder whether personality factors are a strong influence on presentation. Clark et al note that although comorbidity tends to be associated with a more chronic and complicated course, poorer prognosis and lessened response to treatment compared to 'pure' cases, this is also related to disorder severity, regardless of diagnosis. Whilst comorbidity has been identified and considered as a problem with DSM, research has not addressed the more important issues relating to understanding and treating it. It is also interesting to note that research does not appear to have addressed whether ICD-10's combination categories provide a useful means of recording and researching comorbidity.

Coverage

The relationship between comorbidity and heterogeneity has been noted by Sonuga-Barke (1989) and Clark et al (1995). Carr (1999) expresses this clearly, stating that the narrowing of categories to increase homogeneity has led to many cases not meeting criteria and being diagnosed NOS. Clark et al note that there needs to be a balance between the number of categories, within-category homogeneity and comorbidity. They report that the NOS diagnosis is common within the category of mood disorder and wonder whether this should be elevated to a new condition. They note that the NOS diagnosis might be a result of the equal weighting given to the different symptom dimensions within diagnosis and would therefore occur less frequently if diagnoses had some required criteria, and appears to be related to severity, as it occurs more frequently in community samples. This raises the question of whether diagnosis is warranted in such cases, or whether such individuals represent a position on the normal continuum which should not be unnecessarily pathologised. These issues are important
to consider in the utilisation and ongoing development of classification systems, particularly as Clark et al note that it is difficult to remove conditions from classification systems, as they tend to become reified once included within a system, even when their use is rare.

Reliability

The reliability of a classification system cannot be separated from the reliability of its assessor(s) and assessment technique(s). Jensen et al (1995) investigated the test-retest reliability of the DISC using DSM-IIIR diagnoses. With 97 clinical and 278 community children aged between 9 and 17, they obtained moderate and satisfactory reliability data. They report that reliability was enhanced among the clinical population, which is not surprising since the DISC was developed for use with this population, and was higher for participants with ‘externalising’ conditions such as Attention Deficit Disorder (ADD), conduct or oppositional disorder, as compared to ‘internalising’ conditions (mood and anxiety disorders). The authors suggest that repeating an interview is extremely influential, as children learn to adjust their responses to meet their agenda, but do not attempt to address this systematically.

Hoghughi (1992) reports that the reliability of DSM-III and ICD-9 varies according to the condition. Those that are more readily observable, e.g. ADD with hyperkinesis, demonstrate high reliability. This is consistent with Jensen et al’s results. Sonuga-Barke (1998) endorses this and adds that training is required to achieve high reliability data, although the same standards are not applied in everyday practice. In Jampala, Sierles and Taylor’s (1986) survey, practising psychiatrists reported that only half of the patients they diagnose meet all of the required criteria. Unfortunately, Jampala et al do not report what proportion of their participants worked within child and adolescent psychiatry so the applicability of these results to the diagnosis of children and adolescents is somewhat problematic. Anticipating that there may be a difference between the reliability of diagnosis within research projects and everyday practice, it is important to acknowledge that data obtained in research are also only relevant to the
methodology investigated when it is used within similar settings. Enhancing the reliability of diagnosis within everyday practice remains a significant challenge.

Validity

Jampala et al (1983) reported that concerns regarding validity were the most frequently expressed criticism of DSM-III among their sample of 557 psychiatrists and 498 psychiatric residents but do not describe these more fully. Carr (1999) argues that no conditions within DSM-IV demonstrate adequate validity according to the identification of their predisposing risk, triggering, maintaining or protective factors, course over time, or response to treatment. Phares (1992) reviews literature suggesting that DSM-III was subject to gender and racial biases. Davidson and Neale (1996) question how this affects the increased likelihood of girls to display internalising conditions and boys to display externalising conditions. It would therefore seem that although validity has received less attention than reliability, it certainly requires research to identify relationships between disorders and change over time and need for which treatment, if any, should be available.

Ethics

Carr (1999) notes the stigma entailed within classification systems which emphasise labelling individuals according to their weaknesses. These concerns seem particularly pertinent to children as they are usually identified by others to require help, whereas adults are more likely to identify their own needs (Davison & Neale, 1996). Phares (1992) describes the problem of circular explanations, whereby the individual’s behaviour is attributed to their diagnosis and their diagnosis is a result of their behaviour, without context determinants. Similarly, Achenbach (1985) outlines relevant information processing biases, whereby further observations of an individual are interpreted in the light of a diagnosis or hypothesis, which compromises objectivity. There is also a power imbalance within diagnosis, such that when a powerful person makes a diagnosis, others’ views are restricted (Hoghughi, 1992). Hoghughi argues that this is heightened by the unnecessary use of jargon, and cites the term 'episodic
dyscontrol syndrome' to describe periodic severe loss of temper in DSM-IV as an example of this. He also argues that some labels, e.g. reading disorder, award an unnecessary pathology.

Practicalities

In Jampala et al's (1986) survey, the second most frequently expressed concern was that DSM-III was excessively complex. Indeed, it includes a huge array of categories and requires diverse information to be recorded on the five axes. Clark et al (1995) question aspects of DSM's organisation, as there are no obvious boundaries between categories, and diagnoses are placed somewhat arbitrarily into one. Although they express the opinion that divisions are predominantly pragmatic, they note that they are influential in shaping the development of class-based journals and clinics. This is less important in the consideration of child and adolescent mental health problems, as these are placed in a single category, but the appropriateness of this is questionable given the broad age range and diverse presenting problems, ranging from pervasive developmental disorders to quite discrete anxiety disorders. Clark et al also express concern that the time delay in relating research to development hindered the integration of data regarding comorbidity into DSM-IV; presumably, changes will be incorporated in future revisions. Phares (1992) notes the relationship between classification systems, societal attitudes and voting committees, using the example of homosexuality. This constituted a diagnosis until eliminated by committee vote; the increasing use of scientific data to inform the development of classification systems should address such difficulties. Finally, Hoghughi (1992) notes that valid comparisons cannot be made between different systems of classification. The possibility of differing constructions of conditions in DSM and ICD has not been ruled-out.
Alternatives to categorical classification

Multi-variate and dimensional models

Achenbach (1985) describes the identification of syndromes using statistical techniques such as factor and cluster analysis to demonstrate patterns of covariance of attributes. Carr (1999) reports that within child and adolescent psychopathology, disorders are commonly organised into the parsimonious internalising and externalising dimensions, which can be subdivided into smaller categories which vary across the age range. Using the CBCL, this approach provides an objective framework for assessment with cut-off points to distinguish the abnormal and can compare differences across raters, time and context.

Various advantages to this approach have been cited, including the emphasis on the severity of difficulties (Clark et al, 1995; Sonuga-Burke, 1998). The internalising and externalising dimensions appear quite robust in research and their stability over time has been demonstrated in longitudinal research (Fischer, Rolf, Hasazi and Cummings, 1984). Kasius, Ferdinand, Van den Berg and Verhulst (1997) contrasted DSM-IIIIR diagnoses obtained via the DISC with syndrome diagnoses obtained using the CBCL with a clinical sample of 231 children and adolescents. They found that 79% of participants who scored within the problem range of the CBCL also met criteria for a DSM diagnosis, but only 59% of those with a DSM diagnosis were within the problem range of the CBCL. They explain this by reference to the CBCL’s assessment of a range of problems and overall dysfunction as compared to DSM, which can identify isolated difficulties.

Although he acknowledges the greater predictive validity of the dimensional approach, Sonuga-Barke (1998) emphasises its fundamental similarity to categories when cut-off points are used. He also notes how unfamiliar the approach is to clinicians. Clark et al (1995, p.124) state that the approach was considered when developing DSM-IV but rejected due to “lack of consensus, issues of clinical utility, and insufficient empirical support”. They question whether dimensions should be based upon severity of
symptoms, symptom or personality traits, genetic vulnerability or biological parameters. They conclude that developments within this approach probably "would not be much of an improvement" (Clark et al, 1995, p.147).

Hoghughi (1992) discusses the difficulty of developing the dimensional approach, as it is dependent on the quality and settings of research. He describes the approach as complex and user-unfriendly. He notes an increased dependency on accurate terminology and lack of information regarding treatment. Carr (1999) notes that the approach does not provide useful information regarding rare syndromes and pervasive developmental disorders, or those with only one symptom, such as encopresis, as these will not easily be detected within its research methodology.

Theory or etiologically based models

Various authors have commented on the possibility of theory-based models of classification. Carr (1999) advocates an interactional systemic approach to address the frequency with which psychological difficulties are embedded within particular contexts. He proposed methods by which family dynamics can be encoded, and predicts that there would be less stigma resulting from such an approach. Volkmar and Schwab-Stone (1996) note that this approach would address the difficulty recording relational and interactional difficulties, where describing one person does not provide sufficient information.

Clark et al (1995) adopt a different position, noting that several contrasting disorders - depression, bulimia, panic disorder, OCD and ADD - respond to anti-depressants, and might therefore share a common mechanism, in which case it would seem practical for them to be grouped together. Similarly, they argue that seemingly diverse disorders which are related to stress and trauma could be grouped together, e.g. PTSD and adjustment disorders. Clark et al argue that this approach might be useful in targeting comorbidity and developing explanations regarding its presentation. However, Sonuga-Barke (1998) states that current knowledge regarding aetiology is insufficient for this to provide a basis for classification. In addition, the development of a theory-
based system for widespread use would seem to demand that all those using it are well-versed and in agreement with the model. This appears problematic, considering the differences of opinion on such matters within and between the different professions using DSM-IV. Despite this, Jampala et al (1986, p.148) cite research which criticises DSM-III for overlooking psychodynamic approaches to diagnosis and it is noteworthy that such an approach might more readily link assessment and treatment.

**Conclusions and beyond classification**

It was stated in the introduction that a good classification system would facilitate communication among professionals, provide a means of organising information and research, inform epidemiology and planning (Carr, 1999) identify who requires treatment, and of what nature (Sonuga-Burke, 1998) and predict outcome and treatment response (Clark et al, 1998). The research reviewed has demonstrated that the current DSM and ICD classification systems do not adequately meet these criteria.

Phares (1992) and Sonuga-Barke (1998) state that it is impossible now to conceive of working within a system where clients’ difficulties were never classified. Phares suggests that there would be chaos, Sonuga-Burke states that categorising is human nature. The flaws with the current system require that classification and its alternatives receive adequate consideration and debate. In their discussion regarding DSM-IV, Clark et al (1995, p.141) suggest that “perhaps no categorical system can classify psychopathology adequately” yet the alternative modes of classification which have been proposed appear equally problematic.

The Professional Affairs Board (PAB) of the British Psychological Society published guidelines in 1999 regarding the use of diagnostic classifications in court reports. Within these, it is stated that “legal proceedings may be greatly assisted by a psychologist offering a diagnosis based on DSM-IV or ICD-10” (PAB, 1999, p.465), although no explanation is given as to how a diagnosis may be beneficial until the final sentence, where it is noted that classification is a communication aid. The research reviewed in this essay has cast doubt upon the usefulness of diagnosis in aiding
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communication. Pilgrim (2000, p.304) advocates the use of formulations to understand "specific presenting problems in specific contexts" and facilitate service planning and risk assessment and management. Lane (2000) notes that such a formulation should be readily linked to available evidence.

Kirk (1989) states that a formulation should provide a description of a client's difficulties, which can incorporate context-specific details, hypotheses regarding predisposing, maintaining and protective factors, and a treatment plan that is derived logically from this information. As some clients are noted to find diagnosis reassuring (Marzilier, 2000), this can be incorporated into the framework as required, but by reference to situational and temporal factors, the overall result is less stigmatising for the individual. It would seem fair to conclude that classification in isolation is not relevant to understanding or treating mental health problems of individuals at any age, but an evidence-based formulation - which may or may not incorporate classification - informs treatment and can be informed or validated by research.
References


Specialist Paediatric Essay

How far can psychological models of chronic illness help in our understanding of adolescents who are HIV-positive?

Discuss the implications for clinical work with HIV-positive adolescents.

June 2001
Year 2
How far can psychological models of chronic illness help in our understanding of adolescents who are HIV-positive?

Discuss the implications for clinical work with HIV-positive adolescents.

Introduction

Internationally, Acquired Immunodeficiency Syndrome (AIDS) poses a relatively new threat to health. It was first recognised in adults and children respectively in 1982 and 1983 (Newell & Peckham, 1991) but represents the sixth most common cause of death among 15 to 24 years olds in the United States (US - Brown, Lourie & Pao, 2000). Brown et al note that more than one million children world-wide are infected.

Newell & Peckham summarise the methods by which Human Immunodeficiency Virus (HIV) is acquired: penetrative sex with an infected person; receiving infected blood during transfusion or sharing contaminated needles or syringes; ‘vertical transmission’ from mother to child during pregnancy, labour or the perinatal period; and, receiving infected tissue or donor transplants or semen donation. Henggeler, Melton and Rodrigue (1992) report 1990 data which demonstrated that female adolescents in the US tended to acquire HIV infection via heterosexual contact and intra-venous drug use (IVDU). Males were more likely to have contracted HIV via homosexual contact or receiving infected blood. Newell and Peckham state that in the United Kingdom (UK), blood transfusion practices were changed in 1985, so the number of people infected by this method has decreased. Within the adolescent population, it can therefore now be assumed to apply only for a minority of older cases.

HIV causes AIDS by damaging the body’s immune system. Studies of adults for whom the time of infection with HIV is known have identified a variable course. Although some individuals demonstrate symptoms of AIDS rapidly, others are asymptomatic for longer, there is consensus regarding a median time of 10 years (Newell & Peckham, 1991). However, among children the disease runs a more rapid course (Campbell, 1997). Barrett and Victor (1998) state that approximately 1 in 3 HIV+ children
infected via vertical transmission will develop AIDS within 12 months. The remaining children demonstrate a more variable disease progression, but most suffer some clinical or immunological symptoms within 1 year. By contrast, those affected during adolescence demonstrate a longer incubation period, which is more similar to that observed in adults (Henggeler et al, 1992).

The more rapid progression observed in HIV+ children would seem to be the major reason why HIV+ adolescents have been a neglected group. It is only as medical understanding and treatment of HIV have progressed that HIV+ children have survived into adolescence. HIV+ adolescents are a mixed group, with some surviving neonatal or childhood infection, and some more recently infected via risky sexual behaviour or IVDU. Although Henggeler et al (1992) stated that adolescents represented less than 1% of all AIDS cases, Rotheram-Borus’ (2000) figures from the World Health Organisation (WHO) show that half of all HIV infections currently occur among those aged between 15 and 24. In the US, she notes an increase of 77% in adolescent HIV infection between 1991 and 1993 and concludes that “HIV is a significant and growing problem among adolescents” (Rotheram-Borus, 2000, p.S33). It is important to note that theories regarding adolescence present this developmental stage as a time of considerable stress, as young people cope with sexual development, rapid physical change and moves away from childhood towards an adult identity (Moore & Rosenthal, 1993). This suggests that adjustment to HIV infection may be especially difficult for this population.

Although a lengthy review of HIV and AIDS signs and symptoms is beyond the scope of this essay, it is important to note that HIV+ children demonstrate greater symptom variability than adults (Henggeler et al, 1992). They may suffer: failure to thrive, fever, gastrointestinal dysfunction, bacterial infections, anaemia, opportunistic infections and/or neurological disease. Campbell (1997) and Brown et al (2000) provide more detailed descriptions of the adverse effects of HIV infection on the developing brain. These result in an increased likelihood of cognitive and language difficulties. Although widely understood, it is important to reiterate that medical interventions for HIV and AIDS involve treating infections and prolonging well-being. There is still no cure.
This essay will describe two psychological approaches to chronic illness in childhood and adolescence before outlining more fully the specific challenges which HIV+ adolescents face. The strengths and limitations of the chronic illness literature in informing clinical practice with this group will be considered.

Models of chronic illness

The developmental perspective

Eiser’s (1990, p3) definition of chronic illnesses as “conditions that affect children for extended periods of time, often for life” would seem to apply to HIV infection and AIDS. She emphasises a developmental perspective to the psychological aspects of chronic illness. This individualised approach involves considering a young person’s developmental level rather than age or IQ in relation to their adjustment to the disorder, communication with staff, treatment compliance and understanding of medical concepts. This implies that there will be change over time. She suggests that responses to chronic illness are influenced firstly by characteristics of the condition itself, e.g. whether it restricts movement or social activities or is life-threatening, secondly by individual characteristics including personality, age, gender and coping style, and thirdly by such family attributes as problem-solving and communication skills. It therefore becomes apparent that there is no simple correlation between the severity of a disease and the young person or their family’s adjustment.

One advantage of this approach is that it views the whole person, and considers their strengths, which might not be related to their illness. Eiser argues that the developmental stage of adolescence predicts that restrictions related to disease and the need for other’s assistance to comply with treatment might give rise to difficult issues related to establishing independence. She suggests that adolescents with chronic illness might experience strong emotions and reject treatment but considers the usual difficulties of adolescence before concluding that this is not necessarily pathological behaviour.
Eiser also briefly considers attachment theory in relation to the separation from family which occurs when young people are hospitalised. Although not made explicit, it is possible that her apparent emphasis on individual oriented interventions relates to this need for the young person to function relatively independently during such periods. The interventions proposed by the developmental perspective include education regarding the condition, enhancing self-care and social skills, improving attendance and participation in school, and bereavement work for the young people and groups to provide information and support for parents. The aim of each of these must be to maximise functioning according to individual and family characteristics.

To consider HIV and AIDS within this perspective suggests that it will have a rather bleak prognosis. Its relation to AIDS makes HIV a life-threatening condition. The method of transmission could be informative regarding individual or family behaviour - e.g. adolescent risky sexual behaviour or parental IVDU - which might be related to deficient problem-solving or coping skills.

The multifactorial approach

Lask and Fosson (1989, p.11) define their psychosomatic approach to illness as assuming an “interdependence of physical and psychosocial factors”. They argue that illness is influenced by a broad range of variables, including developmental, organic, social and psychological and “virtually all disorders have multifactorial causation - multicausality is the rule, not the exception” (Lask & Fosson, 1989, p.4). It should therefore be fruitful to relate this approach to HIV and AIDS. Again, this is an individualised approach, which begins with investigating predisposing factors such as: biological vulnerability, physiological responses to stress, early life experiences, personality characteristics and sociocultural influences. They suggest that people who experience stress as a physical sensation, were exposed to illness during their early years, who are unable to express their emotions verbally and live in a culture where physical ill health is more acceptable than mental ill health are vulnerable to experiencing difficulty coping with illness.
Lask and Fosson argue that stress can operate as a precipitating or triggering factor sparking the onset or exacerbation of symptoms. Illness may then be maintained by such perpetuating factors as primary and secondary gain, reinforcement from others, the individual’s disposition, sociocultural and family characteristics. Thus, those whose symptom provides relief from anxiety or offers additional benefits, who only gain attention by having symptoms, who suffer heightened emotional arousal when unwell, whose culture tends to seek physical explanations for illness or whose families are characterised by discord, over-protectiveness or parental ill-health are more likely to continue to be ill. Although Lask and Fosson state that protective factors have been less widely researched than other aspects of the model, they suggest that they might include: a good relationship with one parent, high self-esteem and adaptability, good social support and recognition of one’s achievement and development.

This model overlaps with Eiser’s developmental approach to chronic illness by considering biological vulnerability, the individual’s personality and family characteristics. It is therefore not surprising that some of the same interventions are advocated, namely individual therapy and education. However, the additional influences considered by this approach introduce further possibilities for intervention, including parenting skills training and family or marital therapy.

In relating this model to HIV and AIDS, it seems possible that it could minimise the role of biology. However, it may offer useful insights into understanding the emotional experiences and behaviours of those attempting to adjust to and cope with HIV infection, which can then be used to develop clinical interventions for those experiencing difficulties.

The suggestions made by these models regarding likely influences on health and possibilities for intervention will now be considered according to evidence regarding some of the specific challenges faced by HIV+ adolescents. The following challenges will be discussed: awareness, stigma and disclosure, mental well-being and coping, context, multiple losses and service issues.
Challenges posed by HIV and AIDS

Awareness, stigma, disclosure and secrecy

Rotheram-Borus (2000) cites data which state that only 7% of HIV+ ‘youths’ in the US are aware of their HIV status. This lack of awareness initially appears problematic not only because these young people might be engaging in behaviours which place others at risk of infection but also because they are not receiving treatments which could prolong their own well-being. However, Rotheram-Borus also reports that only 25% of those who are aware of their HIV+ status are linked to treatment. This is very disappointing and is at odds with the adult HIV literature advocating earliest possible diagnosis and initiation of treatment. Influences on diagnosis-seeking are beyond the scope of this essay, but English (1992) describes the difficulties associated with gaining informed consent with legal minors and the lack of adolescent-specific assessment and treatment services in the US. It will be important to consider not only the legal framework within which adolescents give their informed consent to HIV testing but also their expectations regarding confidentiality or disclosure.

Barrett and Victor (1998) interviewed 10 parents of HIV+ children. In 7 cases, the HIV diagnosis was not made until the child became, frequently very, unwell. This does not seem surprising given that only 1 in 5 obstetricians were aware of the mother’s HIV+ status. The relative contributions of mothers’ fears regarding disclosure and obstetricians’ not routinely requesting such information require further elucidation. However, the outcome is again that young people are being denied the earliest possible medical intervention. The effect of receiving the child’s HIV diagnosis at a time when they are unwell - and children and their families are already under considerable stress - was not ascertained.

The influence of stigma regarding HIV was not directly examined in the research reviewed above, but could well be a factor in deciding whether or not to undergo HIV testing or to disclose known HIV status to others, including medical personnel. Many authors describe the stigma and social isolation experienced by those with HIV. Stigma
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has been related to reduced adherence with treatment (Campbell, 1997 & Brown et al, 2000) poorer adjustment following bereavement (Siegel & Gorey, 1998) and emotional pain, ostracism and a reduced sense of well-being and competence (Brown et al, 2000). Brown et al describe the dilemma faced by parents regarding whether to inform children of their HIV+ status, but relate this disclosure to more adaptive adjustment and reduced isolation despite some distress and anxiety.

Both models advocated the provision of education regarding illness to individuals and their families. Neither this, nor any other medical or psychological intervention, can be provided where HIV+ status has not been detected. As Eiser advocates, providing support and information for parents at this stage could be beneficial in facilitating discussion of HIV with children. The reasons why the women in the study above did not disclose their HIV status to obstetricians were not obtained but, as awareness of HIV status has been related to more adaptive medical and psychological outcomes, it will be useful to consider the educational and support needs of healthcare staff. There is a reliance on these staff to create an atmosphere in which those affected by HIV feel able to share this information and to cope with any difficult emotions which this raises for them. Lask and Fosson's inclusion of sociocultural influences also appears very important in considering perceptions of stigma. This is likely to be a difficult and time-consuming area to change.

Mental well-being and coping

A variety of emotional and behavioural problems have been associated with childhood HIV infection. Brown et al (2000) note that epidemiological data is scarce, and has tended to be confounded by the consideration of isolated symptoms rather than diagnoses, has not always isolated confounding variables and has sometimes employed rather small sample sizes. They present research which identified an Axis 1 (American Psychiatric Association, Diagnostic and Statistical Manual of Mental Disorders - 4th edition, DSM-IV, 1994) diagnosis in 85% of 34 HIV+ adolescents, including major depression in almost half. This project used a standardised clinical interview to identify disorder but Brown et al note that depression may be confounded with
neurophysiological factors, e.g. withdrawal due to the physical pain experienced by the majority of young HIV sufferers. They therefore suggest that standardised assessment schedules be devised for use with this population. Brown et al also cite 2 research studies which found increased rates of anxiety in HIV+ children. One of these contrasted HIV+ and HIV- children with haemophilia and identified higher rates of anxiety disorder among the HIV+ children. Unfortunately, the total sample size was 23. The second, larger, study, with 101 participants, used parental ratings to identify significantly higher rates of both state and trait anxiety, and depression among HIV+ children than among children with other medical conditions, including cancer.

Campbell (1997) cites research which demonstrates an elevated incidence of attentional and hyperactivity disorders in HIV+ children over the age of 4. He questions whether these are a direct effect of HIV via damage to the basal ganglia, but describes the difficulty of isolating the influences of maternal IVDU, psychosocial factors including chronic illness, stigma, secrecy, shame and loss, and "poverty, drug use, parental infection and/or death, bereavement...discrimination...poor access to medical and other kinds of support and missed schooling" (Campbell, 1997, p.6).

There is a clear need for further epidemiological research, particularly with HIV+ adolescents, whose emotional difficulties are not well understood. In addition it will be useful for clinicians to have evidence describing the particular issues underlying their emotional disturbances. Suggestions have been made regarding the specific issues with which HIV+ adolescents struggle. Brown et al (2000, p.87) identify an extensive list, including: "social stigma, isolation and hopelessness, forced disclosure, anxiety about their medical prognosis, loss and bereavement, and physical appearance and body image" with resultant "social withdrawal, depression, loneliness, anger, confusion, fear, numbness and guilt". This suggests that an extremely thorough and sensitive assessment will be required to ensure that therapy is appropriately oriented. Lask and Fosson's approach is likely to be more useful, by drawing clinician's attention to a broader range of influences.
Brown et al cite research which demonstrated that HIV+ adolescent haemophiliacs still experience distress when presented with reminders of their HIV status, years after learning of their diagnosis. Their sample size of 297 affords this result some generalisability within this population, although the long term adjustment of those affected via different modes remains unknown. This research also identified a range of coping techniques including resignation, self-calming, distraction, self-blame, engagement in risky sexual practices and use of drugs and alcohol. It is possible that there is a vast need for clinical psychologists and/or other health professionals to assist adolescents to adjust to their HIV status. Although Brown et al cite research which enhanced safer sex behaviour among HIV+ adolescents, this is only one outcome measure. There is a need for further research, using a range of measures of adjustment.

There is also little evidence regarding the effectiveness of different interventions for emotional or behaviour problems in this population. Campbell (1997) suggests that behavioural interventions will be useful to address treatment compliance. He also advocates social skills training and play therapy for children. Brown et al (2000) note that HIV+ children and adolescents are likely to benefit from the same interventions offered to those without HIV, although they may be more sensitive to psychotropic medication. He describes pain management as a priority and infers from work with HIV+ adults that cognitive behaviour therapy (CBT) may be useful for anxiety. These interventions overlap quite considerably with those advocated by Eiser. The application of family therapy, as indicated by Lask and Fosson, may also prove to be useful.

Individual and family context

One factor which seems likely to influence an individual’s coping is how their family copes. There is increasing evidence that families affected by HIV are simultaneously experiencing other adverse circumstances. Brown et al (2000) note that multiple losses, parental drug use and parental mental health problems affect many HIV+ children. Campbell (1997) reports that socio-economic deprivation, refugee status, housing problems and social isolation are common. Each of these variables is known to
pose a risk factor to health which, combined with HIV, seems particularly disheartening. Campbell continues to describe the increased difficulty in families where a parent is also affected by HIV, noting that parents frequently feel depressed, anxious and guilty.

Niebuhr, Hughes and Pollard (1998) surveyed 77 HIV+ parents, whose children ranged from infants to age 48. 56% of participants stated that their children knew their parents’ diagnosis, 35% did not and 10% of parents were unsure. Unfortunately, these data were not analysed according to the children’s ages. It would be useful to know when parents tended to disclose their HIV+ status to their children and how they and their children coped with this. The uncertainty and lack of knowledge in some cases may have reflected parental difficulty and a need for support in discussing HIV with their children. It has been suggested that possessing information regarding one’s own HIV+ status facilitates adjustment and coping; further research could usefully investigate the effect of disclosure regarding the HIV+ status of other family members. Niebuhr et al also found that 47% of participants were worried about who would care for their children after their death and 53.5% were worried that their children would be discriminated against on the grounds of parental HIV infection. 67% felt that their children would benefit from having someone with whom to discuss parental health and half wanted help in dealing with their children’s concerns. Although this study did not address children’s HIV status, parental guilt or the quality of relationships between parents and their children, it suggests that there are a range of issues which may worry HIV+ parents. The authors conclude that clinicians should be alert to the possibility of children and adolescent’s concerns regarding parental health in HIV and other services, describing this as one of the five most common worries during adolescence.

Less has been written regarding the impact of HIV+ status on sibling relationships. Brown et al note only that relationships may be impeded by fears regarding contagion or resentment towards the infected child. They state that siblings may also experience stigma and rejection from others relating to the HIV infection. The specific needs of this group would seem to require urgent attention.
As has been implied by the inclusion of refugee status among the potential social stressors operating on families affected by HIV, there is a vital need for services to consider the cultural context of their clients. Campbell (1997) notes that whereas in the US, maternal infection has most frequently occurred via IVDU, in the UK, the main route of maternal infection has been heterosexual contact, and children and adolescents tend to be affected by vertical transmission. It may therefore be that these children are most at risk of suffering multiple losses. Two-thirds of HIV+ children and adolescents in London have parents from sub-Saharan African countries. When working with these families, clinicians need to consider and be prepared to work with: refugee status and residency issues, social isolation, language barriers, and cultural differences in childcare practices, parenting roles and understanding of illness.

Due to the almost infinite variety of beliefs and attitudes, it is difficult to suggest general rules for those working with people from different cultural backgrounds. There are likely to be many exceptions and differing degrees of conviction with which different beliefs are held. Brown et al (2000) suggest that ethnicity influences illness-related coping and therefore, those working with individuals or families should consider and explore both the families’ and the predominant sociocultural attitudes and beliefs towards illness and HIV. For example, they note that in India, HIV infection has been associated with particularly strong reactions of shame, humiliation, fear and anger. Wood, Maforah and Jewkes (1998) describe the sexual context of adolescents in South Africa, noting the routine violence and abuse perpetrated by men against women and the helpless, accepting attitude expressed by these women. Such experiences seem likely to impact upon women’s subsequent behaviour, including how they act within healthcare settings which are often dominated by rather powerful male doctors. It will therefore be beneficial for clinicians working with adolescents affected by HIV to attempt to learn about their prior experiences, in order to enhance their formulations and intervention planning.
This is an area within which Lask and Fosson’s model is likely to prove more useful, as it considers sociocultural and family characteristics in both assessment and intervention. By contrast, Eiser only considers family characteristics in assessment.

Multiple losses

One of the unique features of HIV infection as compared to other chronic illnesses is the increased likelihood that more than one family member will be infected. In 1991, it was estimated that there were between 14,500 and 18,200 ‘AIDS orphans’ (Siegel & Gorey, 1989). Campbell (1997) suggests that these young people are more likely to suffer pathological grief, as they attempt to cope not only with the death of their parent(s), but also with the realisation that they too have a terminal illness and will die, without parental support. Brown et al (2000) cite research stating that adolescents who lose family members to AIDS are likely to suffer depression, suicide, somatisation, conduct disorder, low self-esteem and poor academic performance. There is therefore a great responsibility for professionals to be sensitive to these families’ needs, whether undertaking formal bereavement work themselves or facilitating families’ addressing their own needs.

Siegel and Gorey (1998) explore bereavement literature and conclude that AIDS losses are indeed likely to be hampered by multiple losses and stigma. They note that stigma is associated with the absence of social support, reduced opportunities to discuss the loss and conflicting feelings regarding the deceased and one’s own condition. In addition, they suggest that experiencing multiple losses may precede ‘bereavement overload’, as described in the older adult literature, survivor guilt or the lack of any sense of security. They note the importance of planning child care prior to the death of carers to ease the transition for their children and, often, enable siblings to remain together.

Some interventions for AIDS orphans are geared towards the extended family (Brown et al, 2000 & Niebuhr et al, 1998). Brown et al report theoretical insights regarding the importance of expressing unresolved anger towards the deceased. It seems likely that
families may find this difficult, which would imply that this is an important role for professionals working in this area and could increase as the role of extended families develops. These authors also describe a cognitive-behavioural intervention for the adolescent offspring of HIV+ parents. This included addressing reactions to parental illness, planning for parental death and dealing with the bereavement. Unfortunately, outcome data are not reported.

It is interesting that the bereavement needs of HIV+ children and adolescents appear to have received more attention than their other needs. Perhaps this will change as HIV+ children, adolescents and adults continue to survive for longer. Lask and Fosson's implied under-emphasis on medical factors including course and prognosis may be related to the absence of interventions for bereavement in their list of recommended interventions. However, bereavement work is included by Eiser.

Services

This section will consider various issues relating to the provision of services for HIV+ adolescents. There will be an emphasis on the role of clinical psychologists within these services. It is disappointing that neither model comments explicitly on the relationship between illnesses and the required services.

It has become evident over the course of this essay that families affected by HIV demonstrate quite varied needs. Schable et al (1998) interviewed 922 mothers with HIV or AIDS to gain information regarding their care-taking arrangements. Half of these women were sole caregivers, and most were of low socio-economic status. Although this research was conducted in the US, it can be assumed that there will still be a considerable need for adequate and available childcare facilities for such mothers in the UK. Rotheram-Borus (2000) describes the wider need for economic and social development, which could simultaneously tackle some of the social problems, e.g. IVDU and risky sexual behaviour, associated with HIV infection. She also considers a range of settings within which healthcare could usefully be provided for adolescents, including various methods of conducting preventative work in schools. English (1992)
also argues that adolescent-specific services are required, to provide HIV testing, counselling and treatment, and to co-ordinate participation in clinical trials. It would seem that adolescents themselves could be particularly useful in the planning and development of such facilities.

Barrett and Victor (1998) raise the issue that, since child and adolescent HIV are relatively new areas of medicine, services currently need to be rather specialised. This tends to mean that families travel to hospitals which provide for a relatively wide geographical region. This contrasts with adult HIV services which have become increasingly community-orientated, and can impose transport, and therefore financial, difficulties. Barrett and Victor also suggest that co-ordination with adult services can be problematic. This is important both where parents are also affected, and in the transfer from adolescent to adult services. Based on their interviews with parents of HIV+ children, they suggest a move away from the traditional gay male oriented HIV and AIDS clinics towards ‘family clinics’ which could meet the specific needs of families where several family members are infected.

In the meantime, Henggeler et al (1992) emphasise the important of psychologists working collaboratively with other healthcare professionals as members of multi-disciplinary teams, providing a range of assessments and interventions, consultation and research. As with other chronic illnesses (Eiser, 1990), psychologists may usefully be able to improve adherence with antiretroviral treatment, which can enhance both medical and psychological functioning. One area which has not yet been raised is the specific contribution of neuropsychology to the assessment and co-ordination of interventions to improve cognitive and linguistic functioning where appropriate. In addition, there could be a role working to educate health professionals and examining their attitudes towards HIV. Although not considerable time has passed, Henggeler et al stated that there was a dearth of knowledge and negative attitudes were too often evident to patients.
Conclusion

It is important to acknowledge that this essay has attempted to focus on general issues within the HIV+ adolescent population. Time constraints have permitted consideration of specific subgroups, e.g. adolescents who have contracted HIV via consensual homosexual contact (explored in relation to self-esteem by Davies, 1996). Issues surrounding safe sex practices for HIV+ adolescents have not been explored, nor have theories and research regarding general HIV preventative work. This is not to underestimate their importance.

To return to Eiser’s model of chronic illness, it seems fair to say that it makes some contributions to our understanding of HIV in adolescents. Firstly, it predicts that the terminal nature of HIV will be problematic, this was borne out in consideration of multiple losses. Consideration of issues regarding disclosure also suggested that family’s communication will be influential. The absence of evidence regarding adaptive or non-adaptive characteristics of the individuals infected with HIV suggests a potential area for future research. There is insufficient literature regarding coping within this population. This model also posits interventions which have been supported by the evidence presented, these are bereavement work and education.

The Lask and Fosson approach casts a wider net and it is therefore not surprising that it considers a broad range of potential influences. The evidence presented has suggested that, of these, exposure to parental illness and sociocultural factors are of crucial importance in the consideration of HIV. It is interesting and encouraging that these authors’ inclusion of family therapy has been mirrored in the suggestion of family-oriented services providing medical care. These authors also advocate the provision of individual therapy, which the evidence has suggested has a range of potential focuses.

In conclusion, it is apparent that there is insufficient evidence regarding the specific needs of HIV+ adolescents. Although both models provide some useful insights into the issues facing this population, neither provides a comprehensive framework. A more
useful approach may well need to be specific to HIV, due to some of its more unusual
difficulties - stigma, multiple losses, the influence of different methods of transmission -
and its association with a range of adverse life circumstances.
References


OVERVIEW

This section contains summaries of the five clinical case reports undertaken during the three years of training, as well as summaries of clinical experience gained during each placement. Full details of case reports and placement experience, including placement contracts, logbooks, evaluation forms and correspondence can be found in volume 2 of the portfolio.

All client names and identifying details have been changed throughout this section to preserve confidentiality.
The assessment and treatment of obsessive-compulsive disorder (OCD).

Reason for referral

Jane was referred to the Community Mental Health Team (CMHT) Psychology service by her General Practitioner for advice regarding “obsessional personality”. Jane was in her late twenties, living with her partner and self-employed.

Assessment

Assessment interviews revealed that Jane demonstrated the following symptoms of OCD: intrusive thoughts regarding death and illness, burglary, fire and flooding; ritualistic neutralising of negative intrusive thoughts; repetitive checking of electrical appliances, doors and windows; avoidance of news programmes or papers; and repeated washing of hands and clothing.

Baseline data were collected using the Maudsley Obsessional-Compulsive (MOC) Inventory (Hodgson & Rachman, 1977), and the Responsibility Interpretations Questionnaire (RIQ) and Responsibility Attitudes Scales (RAS; Salkovskis et al, 1999). Results on each scale were in the clinical range.

Formulation

Jane’s symptoms were consistent with a diagnosis of OCD according to the Diagnostic and Statistical Manual of Mental Disorders 4th edition (DSM-IV; American Psychiatric Association, 1994). Salkovskis, Forrester and Richards’ (1998) cognitive behavioural model of OCD was used to explain Jane’s symptoms. This focuses on the role of interpretations of intrusive thoughts and beliefs regarding personal responsibility for causing or preventing harm.
Treatment

Jane was seen for ten therapy sessions, during which a range of cognitive and behavioural techniques were used. These included socialisation into the cognitive-behavioural model and formulation, cognitive restructuring and verbal reattribution strategies, behavioural experiments, and graded exposure to the feared stimuli.

Outcome

At the end of treatment, Jane reported a range of positive effects. These included feeling happier, more productive and more assertive, increased enjoyment of social interaction and a decrease in the frequency of intrusive thoughts. Each of the objective assessments used demonstrated significant improvements.

References


People with Learning Disabilities Case Report Summary

An Assertiveness group for women with learning disabilities.

Referral and Background

Staff from a day centre for adults with learning disabilities contacted the psychology department requesting assertiveness training for several female service users. Nine service users participated in the group. They were aged between 25 and 48 years (mean 32) and most lived with their parents or in group homes.

Assessment

Keyworkers at the Day Centre completed referral questionnaires regarding service users they wished to be considered for the group. Assessment sessions were also carried out with individual service users by the group facilitators. Weston and Went’s (1999) measures of assertiveness and self-esteem were completed.

Treatment plan

Each service user assessed was invited to an assertiveness group. The group aimed to “promote self-esteem and encourage assertive communications...[and]...develop a greater insight into what constitutes “being assertive”” (Millner & Dalby, 1992, p.21). To facilitate the transfer of knowledge and skills beyond the group itself, a letter was sent to Keyworkers at the Day Centre and at group homes, defining assertiveness and outlining how staff could help group members to practice and develop their skills.

Eight sessions of one hour’s duration were conducted over 11 weeks by two Trainee Clinical Psychologists. Session content was adapted from Millner and Dalby (1992) and Weston and Went (1999). Pictures and Makaton signs and pictures were used wherever possible.
Implementation

Sessions began with exercises designed to boost self-esteem, for example group members taking turns to talk about an experience of success during the previous week, or complimenting each other. Participants learnt to define assertiveness, distinguish it from angry or passive behaviour, and increased their emotional awareness. Behavioural techniques were used to help group members explore strategies for dealing with negative emotions, anger management, saying 'No', and making choices and requests.

Outcome

Mean outcome data demonstrated a non-significant increase in assertiveness and a decrease in self-esteem. One participant demonstrated a significant increase in assertiveness, but two demonstrated significant decreases in self-esteem (reported to Keyworkers and the Psychology Head of Department for further evaluation).

Reformulation and Critique

Post-intervention results might have represented increased insight into participants' behaviour. Alternatively, further sessions might have been required to demonstrate change. Time constraints did not enable discussion or assessment of behaviour outside of the group.

References


Children, Adolescents and Families Case Report Summary

The psychometric assessment and differential diagnosis of an eight-year old boy referred to the Attention Deficit Hyperactivity Disorder (ADHD) Clinic.

Referral

Toby was referred to the Child and Adolescent Psychology and Psychiatry Service by a Paediatric Specialist Registrar. The referral letter described Toby as hyperactive and restless, with difficulty interacting with his peers, and a family history of mental health problems.

Assessment

Initial assessment identified behavioural, social and emotional difficulties. A long history of over-activity was reported, which had begun to cause problems at school. Toby had been bullied since beginning primary school, preferred to play on his own, had periods of intense distress and a restricted range of interests.

Conner Behaviour Rating Scales - revised edition (Conner, 1990) completed by Toby’s teacher and parents reported clinically high scores on hyperactivity and restlessness-impulsivity, elevated anxiety-shyness, social problems (low self-esteem and isolation from peers), ADHD, DSM-IV inattention and hyperactivity/impulsivity.

Initial formulation

It was felt that the difficulties reported above might be due to either ADHD or an autistic spectrum disorder. In addition, the family history of mental health problems was felt likely to be a key influence on Toby’s behaviour. The following tests were administered to determine likely explanations for Toby’s difficulties:
Children. Adolescents and Families Case Report Summary

• Wide Range Attainment Test - 3rd edition (WRAT-3, Wilkinson, 1993)
• Happe’s advanced test of theory of mind (Happe, 1994)
• Children’s Depression Inventory (CDI, Kovacs, 1992)
• Asperger Syndrome Diagnostic Interview (Gillberg & Gillberg, 1991)
• Rorschach Inkblot Test (Exner, 1995)

Outcome

Toby obtained Verbal and Performance IQ scores in the ‘superior’ and ‘very superior’ ranges, with lower performance on the Freedom from Distractibility Index. His WRAT-3 scores were also lower, suggesting under-achievement at school. Toby demonstrated difficulty completing the Theory of Mind test and met criteria for Asperger Syndrome on the Diagnostic Interview. The CDI and Rorschach suggested mild depression.

Conclusions and Recommendations

A diagnosis of Asperger Syndrome was made, which prohibited the diagnosis of ADHD. Arrangements were made for Toby to attend a social skills group, and he was referred to Educational Psychology to address the discrepancy between his measured ability and current performance at school.

References


For test references, see Clinical Dossier in Volume 2 of this portfolio.
Specialist Paediatric Case Report Summary

The Assessment and Cognitive-Behavioural Treatment of a 14 year old girl with Post-Traumatic Stress Disorder (PTSD) following a car accident.

Referral

Samira was referred to the Paediatric Psychology service by a Consultant Paediatrician who had noticed that since being involved in a car accident, she had become scared of going in cars, had difficulty sleeping and with schoolwork, and had experienced an increase in epileptic seizures.

Assessment

Samira reported experiencing intrusive thoughts, flashbacks and nightmares about the crash and nocturnal enuresis. She avoided going in cars and going out with her friends. Her family tended not to talk about the accident, and Samira had not discussed it with her friends. The Children’s Impact of Event Scale (IES, Yule, 1997) demonstrated high levels of both intrusion and avoidant symptomatology.

Formulation and treatment plan

Samira’s symptoms were consistent with a diagnosis of PTSD. Although other members of Samira’s family were also experiencing some PTSD symptomatology, they felt that their difficulties were resolving and did not warrant professional intervention. It was therefore decided to conduct individual therapy with Samira.

Foà and Kozak’s (1986) cognitive theory of PTSD was used to guide intervention. This advocates exposure to feared stimuli and consideration of information which is incompatible with the ‘fear network’ to facilitate assimilation of the trauma-related and existing memories. The recommendations of other authors to include cognitive and anxiety management techniques into this process were also incorporated.
Treatment

Samira was actively involved in determining the goals and pace of therapy. She was initially very reluctant to talk about the crash, for fear of increasing her symptoms. The rationale for each component of therapy was shared with her, to reduce this fear.

She decided initially to focus on sleeping in her own room, and a behavioural programme was devised to support this. This proved effective very quickly, despite continuing nightmares. Relaxation techniques were taught to help Samira manage her nightmares and exposure work effectively explored the possibility of ‘worry periods’ and changing images. Later sessions involved cognitive restructuring of beliefs regarding the likelihood of involvement in future car crashes and helped Samira to plan to tell her friends about the accident. Samira spontaneously began spending more time with her friends, and activity scheduling techniques were discussed to help her to plan to gradually increase the frequency and duration of such times.

Outcome

Re-administration of the IES during the final session demonstrated a total score of 9, which is well below the cut-off of 17. Samira and her father were both pleased with the qualitative differences they had observed.

References


Older Adult Case Report Summary

The neuropsychological assessment of a 72 year old man complaining of memory problems.

Referral

Mr M was referred to Psychology by a Consultant Psychogeriatrician for assessment of word-finding difficulty and memory problems.

Initial assessment

Mr M described a 15-20 year history of forgetting names, dates and places, which caused him to retire earlier than planned. Over the last 1-2 years, he had begun to have difficulties with spelling and writing. Mr M performed at a high level throughout his education, and his career as an Engineer. He lived with his wife of 48 years, with whom he enjoyed a supportive relationship, had three children and several grandchildren. Mr M stated that he wanted to know the source of his difficulties in order to plan for his future.

Mr M had previously suffered from mild hypertension. He had no history of cerebrovascular accident (CVA), transient ischaemic attack (TIA) or head injury. A CT scan demonstrated mild cerebral atrophy.

Action plan

Hypotheses considered pseudodementia, Dementia of the Alzheimer's Type (DAT) and Vascular Dementia (VaD). The following tests were administered to further understanding of Mr M's difficulties:

Older Adult Case Report Summary

- National Adult Reading Test (NART, Nelson & Willison, 1991)
- Graded Naming Test (McKenna & Warrington, 1993)
- Controlled Oral Word Association (COWA) and Trail-Making Test (both Spreen & Strauss, 1998)
- Hospital Anxiety and Depression Scale (HADS, Zigmond & Smith, 1993)

Outcome

Mr M performed at an extremely high level on the WAIS-III but demonstrated significantly reduced performance on the WMS-III. He also demonstrated reduced performance on the NART, Graded Naming Test, COWA and Trail Making Test. The HADS did not detect any depression or anxiety.

Conclusions and Recommendations

Although not definitive, clinical information as described at interview and test data appeared to support a diagnosis of early DAT (Green, 2000; Kirshner, 2002). This was fed back to Mr M and to the Psychogeriatrician, who would be able to access further areas of support as required.

References


For test references, see Clinical Dossier in Volume 2 of this portfolio.
Adult Mental Health Core Placement Summary

Placement Details


Supervisor(s): Dr Eva Bratslavsky
Dr Christa Rohde (neuropsychological assessment)

NHS Trust: Surrey Hampshire Borders NHS Trust

Base: Guildford Community Mental Health Team (CMHT)

Overview of clinical experience

Setting

The placement was conducted in a large CMHT covering Guildford and the surrounding area. Referrals for psychology were received from health professionals working both internally and externally to the CMHT, most commonly GPs, Psychiatrists and Community Psychiatric Nurses. Neuropsychological work was undertaken in an out-patient psychiatry department in Frimley.

Models

The placement offered the opportunity to work therapeutically within a cognitive behavioural framework. Extended assessments were conducted with clients with particularly complex needs, utilising psychodynamic principles.

Clinical experience

Clinical work was undertaken with 1 male and 9 female clients aged 23-56 years. Presenting problems included: panic disorder, obsessive-compulsive disorder, post-traumatic stress disorder, depression, sexual abuse, insomnia, bereavement, relationship issues, psychosexual disturbance and self-harm. Cognitive assessment was
undertaken, using: Wechsler Adult Intelligence Scales - third edition, British version (WAIS-III, UK), Wechsler Memory Scales- third edition, British version (WMS-III, UK), National Adult Reading Test (NART), and Rey 15 item figure test.

Meetings, observations, visits and other experiences

In addition to regular attendance at Psychology Locality and Psychology Research Group meetings, meetings at the CMHT and eating disorders service were attended. These covered a range of clinical, research and organisational issues.

Observation of psychologists and other health professionals occurred within the CMHT, neuropsychology service, mental health rehabilitation service, acute psychiatric ward, family therapy service, Crisis Response Team and Assertive Outreach Team. The forensic service and Social Services Resource Centre were also visited.

Research

The service-related research project was commenced during this placement. This involved a comparison of presenting difficulties as described by referrers', and by psychologists in their assessment reports. Full details can be found within the research section of this portfolio.
People with Learning Disabilities Core Placement Summary

Placement details

Dates of placement: 13 April 2000 - 29 September 2000
Supervisor(s): Ms Tessa Lippold
NHS Trust: Surrey Hampshire Borders NHS Trust
Base: Frimley Community Learning Disability Team (CLDT)

Overview of clinical experience

Setting

The placement was based in the psychology service of an outpatient community learning disability team. The service was part of a multi-disciplinary team, including Psychiatry, Nursing, Speech and Language Therapy, Occupational Therapy, Physiotherapy, Music Therapy and Aromatherapy. The team also provided input to a specialist behavioural service.

Models

The majority of work undertaken during this placement used either behavioural or cognitive-behavioural models. In addition, one assessment incorporated Personal Construct Theory.

Clinical experience

Clinical work was undertaken with 8 female and 6 male clients aged 22-62 years, with learning disabilities which ranged from borderline to severe. Presenting problems included: challenging behaviour, in the form of self-injurious behaviour, verbal aggression, continuous demanding of staff attention and anger management;
vulnerability within sexual relationships; dementia; encopresis; low self-esteem; depression; and obsessive-compulsive disorder (OCD). Intervention work was carried out both directly with service users, and indirectly, via working with staff groups. A group was also conducted, jointly with another trainee, to address assertiveness for women with learning disabilities. An extensive range of assessment tools were utilised, including: Wechsler Adult Intelligence Scales - third edition, (WAIS-III, UK); the Bournewood Assessment for Dementia in Downs syndrome; British Picture Vocabulary Scales (BPVS); 'Not a Child Anymore'; Gilliam autism rating scale; Schonell reading test; Neale Analysis of Reading Ability; Hampshire Assessment of Living with Others (HALO); Raven's Coloured Progressive Matrices; Leiter International Performance Scales; and behavioural observation using momentary time sampling. The placement also provided opportunities for joint working with other members of the multi-disciplinary team, e.g. Community Nurses.

Meetings, observations, visits and other experiences

CLDT and Service Development meetings at the Specialist Behavioural Service were attended regularly. Observations of other professionals within the team were conducted, including the Psychiatrist, physiotherapist, Portage worker and community nurses for adults and children with learning disabilities. A respite service and school for children and adolescents with severe learning disabilities were visited. A training day regarding Behavioural Phenotypes and The British Psychological Society (BPS) Special Interest Group (SIG) for People with Learning Disabilities were attended.
Children, Adolescents and Families Core Placement Summary

Placement details

Dates of placement: 12 October 2000 - 23 March 2001
Supervisor(s): Dr Frances Goodhart
                   Dr Angel Adams
NHS Trust: South West London & St George's Mental Health NHS Trust
Base: Sutton Hospital Child & Adolescent Psychology Service

Overview of clinical experience

Setting

This placement was located in the Child and Adolescent Psychology service of an out-patient Child and Adolescent Psychology and Psychiatry department. In addition to psychologists and psychiatrists, music therapists, family therapists and psychotherapists worked for the service. There was an in-patient unit attached to the service, which provided care for children aged 8 to 13 during the week and a weekly Attention Deficit Hyperactivity Disorder (ADHD) clinic.

Models

The majority of work undertaken during this placement utilised behavioural and cognitive-behavioural models. Psychodynamic and systemic narrative approaches were also considered and used as appropriate.
Clinical experience

Independent clinical work was undertaken with 5 males and 5 females, and joint work was carried out with one supervisor with 2 males. The age range of clients seen was 4 to 16 years. Presenting problems included: behaviour problems following domestic violence and parental separation, arguing with parents, toileting problems, anxiety disorders including obsessive-compulsive disorder (OCD) and spider and needle phobias, emotional & learning difficulties, Aspergers syndrome, ADHD, adjustment to neurofibramatosis, and selective mutism. Assessments were carried out using the Wechsler Pre-School and Child Intelligence assessment scales (WPPSI, WISC), Wide Ranging Attainment Test (WRAT), Children’s Depression Inventory, Maudsley Obsessive-Compulsive Inventory, Rorschach and Happé Theory of Mind test.

Meetings, observations, visits and other experiences

Psychology Department and multi-disciplinary team meetings were attended. Observations were carried out with both supervisors, including within a multi-disciplinary cystic fibrosis team, a feeding clinic and a group for parents of children with ADHD or Aspergers syndrome. Other professionals observed included family therapists. A visit was made to a centre for school refusers and a ward round was attended on the inpatient unit. A presentation was made, and presentations given by clinical psychologists and psychotherapists were attended. Training was given in administering, scoring and interpreting the Rorschach Inkblot test using Exner’s diagnostic system.
Paediatric Specialist Placement Summary

Placement details

Dates of placement: 4 April 2001 - 21 September 2001
Supervisor(s): Dr Laura Tomlinson
NHS Trust: Guy's & St. Thomas' NHS Trust
Base: St. Thomas' Hospital, London

Overview of clinical experience

Setting

This placement involved working with a Consultant Clinical Psychologist, and alongside medical and nursing staff based on wards and in out-patient clinics. All children referred received regular input from a Paediatrician within the hospital. Input was also provided to Neonatal Intensive and Special Care Units.

Models

The majority of work undertaken during this placement utilised behavioural and cognitive-behavioural models.

Clinical experience

Independent work was undertaken with 3 girls and 2 boys, aged between 2½ and 14 years. Cases worked jointly with the supervisor included 7 boys and 4 girls aged between 2½ and 15 years. Relevant medical diagnoses included: headache, asthma, obesity, sickle cell disease, epilepsy, non-organic pain, benign intracranial hypertension, haemophilia, cancer, Poland's and Ehlers Danlos syndromes, juvenile arthritis, alopecia and possible Munchausen by proxy. Presenting psychological issues included: anger
management, poor school attendance and school refusal, post-traumatic stress disorder (PTSD), inadequate emotional support, and behaviour problems, including sleep disturbance and adjustment difficulties following parental divorce. Assessments undertaken utilised: recording charts, observation, Wechsler Objective Reading Dimension (WORD), Wechsler Intelligence Scales for Children - third edition (WISC-III), Bender-Gestalt Test, Impact of Events Scale and Children's Memory Scale (CMS).

Meetings, observations, visits and other experiences

Psychiatry Liaison, Psychology Department and Neonatal Unit meetings were attended regularly. Multi-disciplinary team reviews of individual children's care were attended as appropriate. Observations were carried out of the supervisor working with long-term cases and with parents of children on the Neonatal wards. A specialist asthma nurse was observed conducting an asthma clinic. A one-day conference on 'Attachment and Loss' and a half-day training course on 'Perinatal Bereavement' were attended.
Older Adult Core Placement Summary

Placement details

<table>
<thead>
<tr>
<th>Dates of placement:</th>
<th>10 October 2001 - 14 December 2001</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supervisor(s):</td>
<td>Ms Clare Crellin</td>
</tr>
<tr>
<td>NHS Trust:</td>
<td>Mid Sussex NHS Trust</td>
</tr>
<tr>
<td>Base:</td>
<td>Linwood Community Mental Health Centre for Older Adults, Hayward’s Heath</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Dates of placement:</th>
<th>9 April 2003 - 20 June 2003</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supervisor(s):</td>
<td>Mr Ron Bracey</td>
</tr>
<tr>
<td>NHS Trust:</td>
<td>Surrey Oaklands NHS Trust</td>
</tr>
<tr>
<td>Base:</td>
<td>Community Mental Health Team for Older Adults, East Surrey Hospital, Redhill</td>
</tr>
</tbody>
</table>

Overview of clinical experience

Setting

This placement involved working within two Community Mental Health Teams for Older Adults, composed of Psychologists, Psychiatrists, Psychogeriatricians, Community Psychiatric Nurses, Occupational Therapists and Community Support Workers. Within East Surrey Hospital, input was also provided to a Day Hospital and in-patient ward for older adults with mental health problems, and a multi-disciplinary stroke team.

Models

The majority of work undertaken during this placement utilised cognitive-behavioural, psychodynamic and neuropsychological models.
Clinical experience

Independent work was undertaken with 6 men and 9 women aged between 57 and 93 years. Joint work with the supervisor was undertaken with 1 female service user. Presenting problems included: anxiety disorders, e.g. agoraphobia, swallowing phobia and panic disorder, fear of falling, physical health problems, family relationship problems, unresolved grief, depression, word-finding difficulty suggestive of early Dementia of the Alzheimer's Type, Parkinson's disease and Lewy Body dementia, deliberate self-harm, brain injury and housing issues. Work with stroke patients considered attention, language and memory problems. Assessments utilised included: Beck Depression and Anxiety Inventories (BDI & BAI), Hospital Anxiety and Depression Scale (HADS), Zung anxiety and depression inventories, Repeatable Battery for the Assessment of Neuropsychological Status (RBANS), Wechsler Adult Intelligence and Memory Scales - third edition (WAIS-III & WMS-III), National Adult Reading Test (NART) and the Graded Naming Test.

Meetings, observations, visits and other experiences

Psychology Department, Older Adult CMHT and stroke unit meetings were attended. A meeting was held with the Practice Co-ordinator at East Surrey Hospital to discuss the role of the service and the implementation of the National Service Framework (NSF) for Older Adults, including the single assessment process. Community Psychiatric Nurses, an Occupational Therapist, a Speech and Language Therapist, a Consultant Psychogeriatrician, a General Practitioner and service users with dementia in a residential home were observed. A meeting was also held with the Clinical Psychologist working in the stroke unit at Farnham Hospital, where a ward round was attended. A presentation was made to CMHT staff regarding the cognitive-behavioural approach to understanding and treating anxiety disorders. A training afternoon regarding mental health in older adults and planned reforms to the Mental Health Act, and a talk about medication for stroke patients were attended.
Research

The Major Research Project was commenced and conducted within the East Surrey Hospital placement. This explored the applicability of a cognitive-behavioural model of insomnia amongst an older adult population with mental health problems. A presentation was made to CMHT staff regarding the project, and their involvement with it. Full details of the project can be found within the research section of this portfolio.
Older Adult Specialist Placement Summary

Placement details

Supervisor(s): Mr Ron Bracey
NHS Trust: Surrey Oaklands NHS Trust
Base: Community Mental Health Team for Older Adults, East Surrey Hospital, Redhill

Overview of clinical experience

Setting

This placement involved further work with the Community Mental Health Team (CMHT) for Older Adults with Psychologists, Psychogeriatricians, Community Psychiatric Nurses, Occupational Therapists and Community Support Workers, and with East Surrey Hospital multi-disciplinary stroke team. This team was composed of a Consultant Physician, a Specialist Stroke Nurse, ward-based nursing staff, Neuro-Physiotherapists, Occupational Therapists, Speech and Language Therapists and Social Workers.

Models

Work undertaken during this placement utilised behavioural, cognitive-behavioural and neuropsychological models.

Clinical experience

Clinical experience has been undertaken with 20 adults so far, aged between 57 and 88. Presenting problems faced by clients referred to the CMHT included: bereavement,
depression, anxiety disorders including agoraphobia, memory problems, marital and family relationship difficulties, confusion, Parkinson’s Disease and Lewy Body dementia. An anxiety management group was co-facilitated with another Trainee Clinical Psychologist and a Community Psychiatric Nurse, with 4 service users who attended the Day Hospital. Clients referred via the stroke team included in- and out-patients. Presenting problems included: post-stroke depression and anxiety, mobility difficulties and fears for the future, sleep difficulties, confusion, memory and language difficulties. Educational and support work was also carried out with partners and families.

Meetings, observations, visits and other experiences

Weekly Older Adult CMHT referral and business meetings, and multi-disciplinary stroke unit meetings were attended. The psychologist working at the National Service for deaf people with mental health problems was visited and the in-patient ward round observed. A one-day conference regarding ‘Barriers to working with people with brain injuries’ was attended.
RESEARCH DOSSIER

OVERVIEW

This section contains the research undertaken during the three years of training. This includes the service-related research project carried out in the first year, the literature review completed in the second year, the research logbook and the major research project carried out during the third year. A qualitative research project was undertaken during the second year, but is not included as it was not part of the PsychD assessment process.
Service-related research project

A comparison of referrers’ and psychologists’ statements of difficulties in referrals to a Community Mental Health Team (CMHT) Psychology service.

July 2000

Year 1
A comparison of referrers' and psychologists' statements of difficulties in referrals to a Community Mental Health Team (CMHT) Psychology service.

Abstract

Background: As measured by diagnostic categories, referrers appear to under-report psychological difficulties when referring clients to psychologists. Referrals do not appear to be representative of their local populations.

Objectives: To describe referrals to a CMHT psychology service according to demographic data; to devise categories to classify psychological difficulties according to underlying issues and symptoms; and, to examine differences between referrers' and psychologists' descriptions of client difficulties.

Method: Categories of symptoms and underlying issues were devised from a pilot study. Demographic data, psychological difficulties and the outcome of psychological assessment were then recorded for the 67 referrals received in 1998.

Results: Psychologists identified increased numbers of mental health difficulties as compared to referrers, and mental health professionals identified increased difficulties in their referrals than general practitioners.

Conclusions: Further research is warranted, in this service and others, to ascertain the influence of demographic factors and referral processes upon psychological assessment and treatment.
Introduction

The increasing attention received by clinical audit in psychology journals, e.g. Clinical Psychology Forum is identifying a range of biases in referrals to adult mental health psychology services. McPherson and Murphy (1997) found an over-representation of referrals from lower social classes in GP referrals to an out-patient psychology service in Dundee. Hill, Evers, Thomas and Stevenson (1999) reported that psychologists identified additional difficulties in 35% of their sample of adult mental health referrals made by GPs. These results appear to have important implications for service planning and allocation of clients. Adverse social situations and/or additional psychological difficulties are likely to impact upon the efficacy of psychological work, such that increased duration of intervention or further training might be required.

On reading these articles the importance of conducting audit in individual services becomes clear. For example, reasons for referral have been categorised according to diagnostic categories: McPherson, Watson and Taylor (1996) classified their GP referrals as: anxiety, depression, mixed anxiety and depression, eating disorders, relationship problems and adverse reactions to life events. Similarly, Murray and Hewitt's (1996) clients categorised their difficulties as depression, anxiety, stress, post-traumatic stress disorder or parenting problems. These categories do not address the heterogeneity of clients within any one diagnostic group, do not identify phenomena of interest to psychologists working within different theoretical orientations, e.g. psychodynamic, and do not explain why clients were referred to psychology, rather than another mental health professional.

Hughes, Midence and Jackson (1996) recorded inaccurate identification of the types of difficulties addressed by psychological assessment or intervention among members of a Community Mental Health Team (CMHT). This demonstrates the importance of discussing referrers' perceptions of psychologists and other disciplines, and providing accurate information, to facilitate referral to the most appropriate discipline.
Referrals are made directly to psychologists within Guildford CMHT, most frequently by GPs and other CMHT members. At the present time, there is no formal audit procedure examining referrals to psychologists or other members of the team. This study is therefore an exploratory study of referrals to psychology, focusing on referrers’ and psychologists’ assessments of clients’ difficulties. As the clinical psychologists within the team often work psychodynamically and/or systemically, conventional diagnostic categorisation is not deemed appropriate to describe clients’ needs. Therefore, an experimental system has been devised by psychologists working within this service to categorise symptoms and underlying issues. It is not expected that these issues will be identified by referrers. Reliability and validity checks were conducted.

**Objectives**

1. To describe referrals according to gender, age, marital status, ethnicity, education, occupation, and to devise categories to record mental health difficulties, in terms of symptoms and underlying issues, as described by referrers and psychologists.

2. To examine differences between referrers’ and psychologists’ descriptions of clients’ difficulties, including the number of difficulties. Depending on the numbers of referrals received from different sources, it might be possible to look at differences between referrers.

**Hypotheses**

From the above literature review, it is expected that psychologists will identify additional problems, including underlying issues, to those identified by referrers. Although not predicted by literature, it would seem likely that referrals made by mental health professionals to psychologists would detail increased numbers of difficulties than those made by GPs.
Method

Setting
During 1998, Guildford CMHT employed 1.6 full time equivalent Qualified Clinical Psychologists, and 2 part-time Counselling Psychologists in Training, and served the population living on the Western side of Guildford.

Participants
67 referrals made to Guildford CMHT psychologists between 01.01.98 and 31.12.98. This period maximised recency but avoided staffing changes which occurred early in 1999.

Procedure
Age, gender, marital status and ethnicity were recorded from each file to describe the sample (Appendix 3). Occupation and education were recorded as estimates of social class using, respectively, the categories employed in the Black Report (Black, Morris, Smith & Townsend, 1992, p40) and by Goldblatt (1990, in Whitehead, 1992, p.241). The following variables were all recorded for analysis: referrer’s discipline, qualification status of psychologist offering assessment, length of time before first appointment, attendance at this appointment, and outcome of assessment.

Categorising psychological difficulties was more complex as the department’s practice orientation does not support categorisation solely by symptoms, such as those employed by McPherson et al (1997). Categories acknowledging underlying issues and conflicts were devised to categorise referrals and psychology assessments from a pilot sample of 15 files by the researcher and the Psychology Head of Service. As with the main study, information was gained from assessment reports and notes written during assessment. Although not standardised, the categories devised (see next page) demonstrate particular relevance to the interests of the psychologists using this study by reflecting the needs of individuals using this service according to the needs-led model employed in their assessment and treatment. Categorisation of demographic variables revealed 100% inter-rater reliability.
### Table 1: Categories of client needs derived from pilot study

<table>
<thead>
<tr>
<th>REFERRERS</th>
<th>PSYCHOLOGISTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aggression</td>
<td>Acculturation difficulty</td>
</tr>
<tr>
<td>Anxiety</td>
<td>Anti-social personality disorder</td>
</tr>
<tr>
<td>Attention or concentration difficulty</td>
<td></td>
</tr>
<tr>
<td>Behavioural disturbance (non-aggressive)</td>
<td>Bereavement</td>
</tr>
<tr>
<td>Bipolar disorder</td>
<td>Body image issues</td>
</tr>
<tr>
<td>Cognitive or perceptual problems</td>
<td>Cognitive or perceptual problems</td>
</tr>
<tr>
<td>Communication difficulty</td>
<td>Communication difficulty</td>
</tr>
<tr>
<td>Depression</td>
<td>Depression</td>
</tr>
<tr>
<td>Eating disturbance</td>
<td>Destructive tendencies, e.g., self-neglect &amp; perfectionism</td>
</tr>
<tr>
<td>Emotional suppression or repression</td>
<td>Dissociation, depersonalisation or derealisation</td>
</tr>
<tr>
<td>Employment or legal issues</td>
<td>Emotional suppression or repression</td>
</tr>
<tr>
<td>Expression of dysfunctional emotions</td>
<td>Employment or legal issues</td>
</tr>
<tr>
<td>Family dysfunction</td>
<td>Family dysfunction, e.g., communication, abuse</td>
</tr>
<tr>
<td>Fear of failure</td>
<td></td>
</tr>
<tr>
<td>Financial difficulty</td>
<td>Financial or housing difficulty</td>
</tr>
<tr>
<td>Gender issues</td>
<td>Gender issues</td>
</tr>
<tr>
<td>Guilt, shame or inadequacy</td>
<td>Helplessness, despair or death wishes</td>
</tr>
<tr>
<td>Helplessness, despair or death wishes</td>
<td>High dependency needs</td>
</tr>
<tr>
<td>High dependency needs</td>
<td></td>
</tr>
<tr>
<td>Interpersonal difficulty</td>
<td>Identity difficulty</td>
</tr>
<tr>
<td>Marital dysfunction</td>
<td>Marital dysfunction</td>
</tr>
<tr>
<td>Mood swings</td>
<td>Neurotic maladaptive conflicts/defences, e.g., denial, moral anxiety, blocking memories</td>
</tr>
<tr>
<td>Neurotic maladaptive conflicts/defences, e.g., denial, moral anxiety, blocking memories</td>
<td>Paranoid elements in personality</td>
</tr>
<tr>
<td>Physical health problem(s)</td>
<td>Physical health problem(s)</td>
</tr>
<tr>
<td>Political issues</td>
<td>Poor coping ability</td>
</tr>
<tr>
<td>Poor self-esteem</td>
<td>Poor self-esteem</td>
</tr>
<tr>
<td>Psychosis</td>
<td>Psychosomatic difficulty</td>
</tr>
<tr>
<td>Rage or anger</td>
<td></td>
</tr>
<tr>
<td>Schizoid elements in personality</td>
<td>Schizoid elements in personality</td>
</tr>
<tr>
<td>Self-harm or suicide attempts</td>
<td>Self-harm or suicide attempts</td>
</tr>
<tr>
<td>Social difficulty</td>
<td>Social difficulties</td>
</tr>
<tr>
<td>Splitting defences</td>
<td></td>
</tr>
<tr>
<td>Substance misuse</td>
<td>Substance misuse</td>
</tr>
<tr>
<td>Suicidal ideation</td>
<td>Suicidal ideation</td>
</tr>
<tr>
<td>Victim of neglect</td>
<td>Victim of neglect</td>
</tr>
<tr>
<td>Victim of physical abuse</td>
<td>Victim of physical abuse</td>
</tr>
<tr>
<td>Victim of sexual abuse</td>
<td>Victim of sexual abuse</td>
</tr>
</tbody>
</table>
Results

Demographic variables

27 (40.3%) participants were male, and 40 (59.7%) were female. Average age was 33 (s.d. 11.1; range 17 to 62). 61 (91%) participants were British and White; 4 were European, 1 Chinese and 1 Black non-African or Caribbean. The following figures describe participants' marital status, education level and occupation status.

Figure 1: Summary of participants' marital status (n=67)

Figure 2: Summary of participants' education level (n=67)
Figure 3: Summary of participants’ occupation status (n=67)

Referral

The following chart summarises how many participants were referred by each discipline.

Figure 4: Summary of frequency of referral according to referrers’ professions (n=67)

6 clinical psychologists and 1 ward-based psychiatric staff nurse comprised the ‘other’ category.
Mean waiting time for psychological assessment was 4.48 months (s.d. 2.16; range 1-8). 54 (80.6%) participants were offered assessment by clinical psychologists, and 13 (19.4%) by trainee counselling psychologists.

19 (28.4%) participants did not attend appointments offered for psychological assessment. Their reasons were as follows:

Figure 5: Summary of known reasons for not attending psychological assessment appointments (n=19)

The outcomes of the psychological assessments were as follows (next page):
The 'other' category comprised 1 consultancy referral.

Differences between referral and assessment findings

The mean number of difficulties identified by referrers was 3.39 (s.d. 2.01, range 1-9). The mean number of difficulties identified by psychologists was 8.64 (s.d. 3.72, range 3-18). The Wilcoxon signed ranks test of related groups demonstrated that this difference was significant at the p<.001 level (Z=-5.901).

The mean number of difficulties identified by GPs was 2.6 (s.d. 1.44, range 1-6). The mean number of difficulties identified by all other referrers, i.e. mental health professionals, was 4.25 (s.d. 2.20, range 1-9). The Mann-Whitney test of independent groups demonstrated that this difference was significant at the p=.002 level (Z=-3.127). The number of referrals received from each discipline was considered too small to conduct further analyses of differences.

The following tables demonstrate the categorisation of presenting difficulties identified by referrers and psychologists according to the integrative needs-led model.
Table 2: Summary of difficulties identified by referrers (n=67)

<table>
<thead>
<tr>
<th>Category</th>
<th>Frequency</th>
<th>Percentage</th>
<th>Rank position</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>35</td>
<td>52.24</td>
<td>1</td>
</tr>
<tr>
<td>Anxiety</td>
<td>30</td>
<td>44.78</td>
<td>2</td>
</tr>
<tr>
<td>Family dysfunction</td>
<td>18</td>
<td>26.87</td>
<td>3</td>
</tr>
<tr>
<td>Poor self-esteem</td>
<td>15</td>
<td>22.39</td>
<td>4.5</td>
</tr>
<tr>
<td>Self-harm or suicide attempts</td>
<td>15</td>
<td>22.39</td>
<td>4.5</td>
</tr>
<tr>
<td>Interpersonal difficulty</td>
<td>12</td>
<td>17.91</td>
<td>6</td>
</tr>
<tr>
<td>Eating disturbance</td>
<td>10</td>
<td>14.93</td>
<td>8</td>
</tr>
<tr>
<td>Marital difficulty</td>
<td>10</td>
<td>14.93</td>
<td>8</td>
</tr>
<tr>
<td>Sleep disturbance</td>
<td>10</td>
<td>14.93</td>
<td>8</td>
</tr>
<tr>
<td>Substance misuse</td>
<td>8</td>
<td>11.94</td>
<td>10</td>
</tr>
<tr>
<td>Bereavement</td>
<td>7</td>
<td>10.45</td>
<td>11.5</td>
</tr>
<tr>
<td>Employment or legal issues</td>
<td>7</td>
<td>10.45</td>
<td>11.5</td>
</tr>
<tr>
<td>Physical health problem</td>
<td>6</td>
<td>8.96</td>
<td>13</td>
</tr>
<tr>
<td>Cognitive or perceptual problems</td>
<td>5</td>
<td>7.46</td>
<td>14.5</td>
</tr>
<tr>
<td>Psychosis</td>
<td>5</td>
<td>7.46</td>
<td>14.5</td>
</tr>
<tr>
<td>Suicidal ideation</td>
<td>4</td>
<td>5.97</td>
<td>16.5</td>
</tr>
<tr>
<td>Victim of sexual abuse</td>
<td>4</td>
<td>5.97</td>
<td>16.5</td>
</tr>
<tr>
<td>Expression of dysfunctional emotions</td>
<td>3</td>
<td>4.48</td>
<td>18.5</td>
</tr>
<tr>
<td>Financial difficulty</td>
<td>3</td>
<td>4.48</td>
<td>18.5</td>
</tr>
<tr>
<td>Aggression</td>
<td>2</td>
<td>2.99</td>
<td>21</td>
</tr>
<tr>
<td>Emotional suppression or repression</td>
<td>2</td>
<td>2.99</td>
<td>21</td>
</tr>
<tr>
<td>Victim of physical abuse</td>
<td>2</td>
<td>2.99</td>
<td>21</td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
<td>7.46</td>
<td>23</td>
</tr>
</tbody>
</table>

The 'other' category included 1 case each of: bipolar disorder, gender issues, non-aggressive behavioural disturbance, political issues and social difficulties.
Table 3: Summary of difficulties identified by psychologists (n=47)

<table>
<thead>
<tr>
<th>Category</th>
<th>Frequency</th>
<th>Percentage</th>
<th>Rank position</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>37</td>
<td>78.72</td>
<td>1</td>
</tr>
<tr>
<td>Anxiety, fears or tensions</td>
<td>36</td>
<td>76.60</td>
<td>2</td>
</tr>
<tr>
<td>Family dysfunction</td>
<td>34</td>
<td>72.34</td>
<td>3</td>
</tr>
<tr>
<td>Rage or anger</td>
<td>22</td>
<td>46.81</td>
<td>4</td>
</tr>
<tr>
<td>Poor self-esteem</td>
<td>21</td>
<td>44.68</td>
<td>5</td>
</tr>
<tr>
<td>Interpersonal difficulty</td>
<td>18</td>
<td>38.30</td>
<td>6</td>
</tr>
<tr>
<td>Self-harm or suicide attempts</td>
<td>17</td>
<td>36.17</td>
<td>7</td>
</tr>
<tr>
<td>Marital dysfunction</td>
<td>16</td>
<td>34.04</td>
<td>8</td>
</tr>
<tr>
<td>Neurotic maladaptive conflicts</td>
<td>15</td>
<td>31.91</td>
<td>9</td>
</tr>
<tr>
<td>Psychosexual difficulty</td>
<td>15</td>
<td>31.91</td>
<td>9</td>
</tr>
<tr>
<td>Guilt, shame or inadequacy</td>
<td>13</td>
<td>27.66</td>
<td>11</td>
</tr>
<tr>
<td>Helplessness, despair or death wishes</td>
<td>12</td>
<td>25.53</td>
<td>12.5</td>
</tr>
<tr>
<td>Social difficulties</td>
<td>12</td>
<td>25.53</td>
<td>12.5</td>
</tr>
<tr>
<td>Suicidal ideation</td>
<td>11</td>
<td>23.40</td>
<td>14</td>
</tr>
<tr>
<td>Identity difficulty</td>
<td>10</td>
<td>21.28</td>
<td>16</td>
</tr>
<tr>
<td>Victim of sexual abuse</td>
<td>10</td>
<td>21.28</td>
<td>16</td>
</tr>
<tr>
<td>Employment or legal issues</td>
<td>10</td>
<td>21.28</td>
<td>16</td>
</tr>
<tr>
<td>Destructive tendencies</td>
<td>9</td>
<td>19.15</td>
<td>18</td>
</tr>
<tr>
<td>Bereavement</td>
<td>8</td>
<td>17.02</td>
<td>19</td>
</tr>
<tr>
<td>Physical health problem</td>
<td>7</td>
<td>14.89</td>
<td>20</td>
</tr>
<tr>
<td>Eating disturbance</td>
<td>6</td>
<td>12.77</td>
<td>21.5</td>
</tr>
<tr>
<td>Substance misuse</td>
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<td>12.77</td>
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</tr>
<tr>
<td>High dependency needs</td>
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<td>10.64</td>
<td>24.5</td>
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<tr>
<td>Feelings of insecurity or inferiority</td>
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<td>10.64</td>
<td>24.5</td>
</tr>
<tr>
<td>Mood swings</td>
<td>5</td>
<td>10.64</td>
<td>24.5</td>
</tr>
<tr>
<td>Victim of physical abuse</td>
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<td>10.64</td>
<td>24.5</td>
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<tr>
<td>Acculturation difficulty</td>
<td>4</td>
<td>8.51</td>
<td>27.5</td>
</tr>
<tr>
<td>Victim of neglect</td>
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<td>8.51</td>
<td>27.5</td>
</tr>
<tr>
<td>Attention or concentration difficulty</td>
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<td>6.38</td>
<td>31.5</td>
</tr>
<tr>
<td>Body image issues</td>
<td>3</td>
<td>6.38</td>
<td>31.5</td>
</tr>
<tr>
<td>Communication difficulty</td>
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<td>6.38</td>
<td>31.5</td>
</tr>
<tr>
<td>Emotional suppression or repression</td>
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<td>6.38</td>
<td>31.5</td>
</tr>
<tr>
<td>Financial or housing difficulty</td>
<td>3</td>
<td>6.38</td>
<td>31.5</td>
</tr>
<tr>
<td>Splitting defences</td>
<td>3</td>
<td>6.38</td>
<td>31.5</td>
</tr>
<tr>
<td>Cognitive or perceptual difficulty</td>
<td>2</td>
<td>4.26</td>
<td>37</td>
</tr>
<tr>
<td>Dissociation, depersonalisation or derealisation</td>
<td>2</td>
<td>4.26</td>
<td>37</td>
</tr>
<tr>
<td>Fear of failure</td>
<td>2</td>
<td>4.26</td>
<td>37</td>
</tr>
<tr>
<td>Paranoid elements in personality</td>
<td>2</td>
<td>4.26</td>
<td>37</td>
</tr>
<tr>
<td>Schizoid elements in personality</td>
<td>2</td>
<td>4.26</td>
<td>37</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
<td>8.51</td>
<td>40</td>
</tr>
</tbody>
</table>
The ‘other’ category included 1 case each of: anti-social personality disorder, poor coping ability, psychosis and gender issues.

These tables demonstrate identical ranking of the first three categories: depression, anxiety and family dysfunction, although psychologists identified these difficulties in greater percentages of participants. Referrers and psychologists also identified poor self-esteem, interpersonal difficulty, self-harm or suicide attempts and marital difficulty within the eighth most common difficulties. However, whilst psychologists also identified difficulties with anger or rage within the eight most commonly identified difficulties, referrers identified eating disturbances.

Across all categories, psychologists identified lesser proportions of eating disturbance, psychosis, and cognitive or perceptual problems. In all other categories, they identified greater frequencies of occurrence. Due to the differing sample sizes, these comparisons have been made by examining the observed percentages.

Discussion

Summary of results

Approximately two-thirds of participants were female. This is consistent with McPherson, Watson and Taylor (1996) and McPherson and Murphy’s (1997) results. As previous research does not appear to have discussed participants’ ethnicity or marital status, no comparisons can be made regarding these data.

The most frequently held education achievement appeared to be a university degree, but education level was not available for nearly half of referrals. This does not seem to correspond with McPherson and Murray’s (1997) over-representation of referrals from lower social classes, as measured by postcodes. It is possible that those with more advanced education are more likely to attend appointments for psychological assessment. The data regarding current occupation appeared to be bimodal, favouring intermediate employment and unemployment.
The mean waiting time of 4.48 months was slightly shorter than that achieved by McPherson et al (1997), whose mean of 22.2 weeks is equivalent to 5.18 months. Nevertheless, this is considerably longer than the 12 weeks standard proposed by Murray and Hewitt (1996).

28.4% of participants did not attend any appointments for psychological assessment. Goode (1997) reported failed attendance rates of 17.1% for adult primary care and 28.1% for adult physical health referrals. Such data are extremely important in ensuring that clinicians’ skills are used efficiently and minimising waiting time for all clients. Goode (1997, p.35) suggests that null contacts represent “a failure….to satisfy clients’ needs or meet their expectations”. Identifying and addressing factors which influence clients referred to a CMHT psychology service provides one potential method to tackle waiting times.

As predicted, psychologists identified significantly more difficulties than referrers. This is consistent with Hill et al’s (1999) study, where additional problems were identified in 35% of referrals. This result could be due to specialist training, increased duration of assessment, time elapsed between referral and assessment or other factors.

That mental health professionals identified significantly more difficulties in referrals than GPs suggests that increased duration of assessment and specialist mental health training facilitate the identification of psychological difficulties. The similarity between the difficulties most commonly identified by referrers and psychologists is encouraging, and suggests that both are interested in addressing the same issues. That referrers did not appear to be solely interested in diagnostic categories, but also identified underlying variables, might imply good understanding among referrers of issues of interest to these psychologists. In this service, this suggests that referrers have good understanding of the, frequently psychodynamic and systemic, models employed by the psychologists. This might be a consequence of positive communication between referrers and psychologists, including written feedback regarding the outcome of psychological assessment.
That depression and anxiety were the most common presenting difficulties replicates Murray and Hewitt (1996) and McPherson et al’s (1996) findings. It was beyond the scope of this study to investigate the interactions between different categories, but this might usefully be done in further research. For example, DSM-IV lists sleep and eating disturbance, poor self-esteem, guilt, concentration difficulty and thoughts of death or suicide as potential diagnostic criteria for a major depressive episode. However, the identification of such criteria as distinct categories reflects the heterogeneity within diagnostic groups and would appear to aid individualised formulation and treatment planning.

Methodological considerations

Although the study has demonstrated that it is possible to categorise difficulties according to underlying issues as an alternative to diagnostic systems, the categories devised during the pilot study were not standardised, so their reliability and validity are not known. With the apparent similarity between categories such as self-esteem; guilt, shame or inadequacy; and insecurity or inferiority, it is important to verify that the different psychologists within the service would use these categories in the same way. Replication could usefully engage additional psychologists in devising and categorising difficulties and ensure inter-rater reliability. Validity could be enhanced by contrasting categories with diagnostic criteria and/or objective measures. No attempt was made to assess the severity of difficulties, this could be achieved with objective rating scales, such as Beck Depression Inventory (BDI; Beck, 1987) scores. The research design did not enable matching of individuals at referral and psychological assessment. It is therefore possible that referrers’ and psychologists’ diagnoses, e.g. depression, did not correspond.

Throughout the study, it was assumed that concordance between referrals and assessments is desirable, in both qualitative and quantitative information. This assumption must be challenged until the influence of information gained at referral upon later psychological assessment has been further examined. This information might
either facilitate exploration of important issues, inhibit consideration of factors not previously identified, or have no effect.

Areas for further investigation

Future research could usefully investigate demographic variables and psychological difficulties, including the influence of the bimodal data regarding occupation status and the influence of education level on engagement in psychological assessment and therapy. Eysenck (1994) reports research findings which suggest that psychoanalytic psychotherapy is more effective with highly educated clients. The influence of different lengths of waiting time upon psychological difficulties appears important in predicting clients’ well-being prior to psychological assessment and setting targets for service provision. It therefore requires further research, which might be conducted using a prospective design to assess the presence of difficulties at the time of referral and assessment.

The over-reporting of eating disturbances and psychosis by referrers might relate to their anxiety regarding risk assessment and management. The perception of risk might be a key factor in the decision to refer clients to specialist services. The over-reporting of cognitive or perceptual difficulties implies a lack of certainty regarding the presence of these difficulties, and an understanding that psychologists have more advanced assessment skills in this area. The validity of these suggestions requires further investigation.

It is important to question why referrers used fewer categories than psychologists. They might have been unaware of some issues, did not consider them to be sufficiently important to note or assumed that they would be easily observable to the psychologist. Interviews might usefully be conducted to explore referral processes.

Although the study examined differences between GPs and mental health professionals, sample sizes were too small to address differences within and between disciplines. This might usefully be conducted, and include the influence of communication from
psychologists to referrers. For example, whether oral or written feedback regarding the outcome of psychological assessment influence subsequent referrals, and what information is most important. Another fruitful area might address why referrals are made to psychology as opposed to other disciplines.

Implications for the service

The study has raised several issues for discussion within the team. Firstly, psychologists can expect that clients seen for assessment will present with additional psychological difficulties to those described in the referral. This might hinder service planning and allocation of clients to the most appropriate psychologist in terms of experience and training. Secondly, it may be felt appropriate to feedback the results of this study to referrers, i.e. that there appears to be close agreement between the difficulties identified, although there are frequently unreported difficulties in referrals. The agreement may be a factor of feedback following psychological assessment; this practice should therefore be continued. Additionally, it might be extended to include educating referrers regarding the types of issues which psychologists examine in their practice.

It would also seem beneficial to discuss what information is desirable in referrals. The provision of minimal information might be preferable, in facilitating a bias-free assessment. In this case, psychologists might request sufficient information to make an assessment of risk, and prioritise cases accordingly. Alternatively, more detailed information might be preferred, to facilitate client allocation according to clinicians' training, interests and experience.

Conclusions

This study demonstrated that psychologists in this service identify additional psychological difficulties to those identified by referrers. That mental health professionals identified increased numbers of difficulties than GPs suggests that this
might be an effect of specialist mental health training or increased duration of assessment. Further research is required to determine the influence of demographic data on psychological wellbeing, assessment and treatment and to identify factors which influence the referral process.
References


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Appendix 5  Correspondence regarding the feedback of results
APPENDIX 1

CORRESPONDENCE REGARDING

ETHICAL APPROVAL
Caedicott Guardian
Dr.
Farnham Hospital
c/o
Clinical Psychologist in Training
Community Mental Health Team

Dear Dr. [name]

January 19th 2000

I am writing to inform you of a research project which I propose to conduct as part of my Clinical Psychology training, based at the University of Surrey. I am currently on placement at Community Mental Health Team under the supervision of Dr. [name], Chartered Consultant Clinical Psychologist. As part of my training, I am required to conduct a piece of ‘Service Related’ research.

As such, I would like to investigate demographic variables and clients’ presenting problems, specifically examining differences between referrers’ and psychologists’ perceptions of individuals’ psychological difficulties. This will involve using the files of clients referred to this service in 1998. No names, addresses or dates of birth will be recorded during data collection. The project will be undertaken under the supervision of Dr. [name] and my University-based Research Supervisor.

I understand from that this study does not require ethical approval as the data is already available and will be recorded anonymously. I am writing in the hope that you can confirm this. Please do not hesitate to contact me if you have any queries or require further information.

Yours sincerely,

Clinical Psychologist in Training
Clinical Psychologist in Training
Community MHT

27th January 2000

Dear

Thank you for your letter. I can confirm 's advice that you do not require ethical approval for this study and that the data will be anonymised. I wish you all the best with this project.

Yours sincerely,

[Signature]

Medical Director

cc
APPENDIX 2

DATA COLLECTION SHEET
Age at referral: years

Gender: Male Female

Marital status: Single Married Widowed Cohabiting Divorced

Ethnicity: British/White Indian Black African
Black Caribbean Black Other Pakistani Bangladeshi Chinese
Other (specify)

Occupation (see reverse of sheet): Professional Intermediate
Skilled non-manual Skilled manual Part skilled Unskilled
Unemployed

Highest education level achieved:
Degree Non-degree higher qualification A levels GCSE/equivalent

Referrer: GP CPN Psychiatrist SW Other (specify)

Date of referral: Date of 1st appointment offered:
Time from referral to appointment (to nearest month):

Referrer's statement of difficulties:

| Number of problems: | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | ...
|---------------------|---|---|---|---|---|---|---|---|---|

Attended appointment: Yes No
Allocated to: Clinical Psychologist Counselling Psychologist
Trainee Trainee

Referred to different service:

Psychologists statement of difficulties:

| Number of problems: | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | ...
|---------------------|---|---|---|---|---|---|---|---|---|
APPENDIX 3

CATEGORIES FOR RECORDING

OCCUPATION STATUS
Black et al (1992)

Social class categories according to occupation

**Professional**
Doctor, lawyer, clergy

**Intermediate**
Manager, nurse, schoolteacher, author, MP, farmer

**Skilled non-manual**
Clerical worker, secretary, shop worker

**Skilled manual**
Bus driver, butcher, carpenter, coal face worker

**Partly skilled**
Agricultural worker, bus conductor, postman, bar staff, telephone-operator

**Unskilled**
Cleaner, dock worker, labourer
APPENDIX 4

SUMMARY OF RESULTS
### Table 1: Participants' marital status

<table>
<thead>
<tr>
<th>Marital status</th>
<th>Frequency</th>
<th>Percentage</th>
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<td>Single</td>
<td>28</td>
<td>41.8</td>
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<tr>
<td>Married</td>
<td>23</td>
<td>34.3</td>
</tr>
<tr>
<td>Separated or divorced</td>
<td>7</td>
<td>10.4</td>
</tr>
<tr>
<td>Cohabiting</td>
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<td>3.0</td>
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<tr>
<td>Widowed</td>
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<td>1.5</td>
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### Table 2: Participants' education level

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<tr>
<td>Degree</td>
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<td>17.9</td>
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<tr>
<td>Non-degree higher qualification</td>
<td>11</td>
<td>16.4</td>
</tr>
<tr>
<td>GCSEs or equivalent</td>
<td>9</td>
<td>13.4</td>
</tr>
<tr>
<td>'A' levels</td>
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<td>6.0</td>
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<td>31</td>
<td>46.3</td>
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### Table 3: Participants' occupation status

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<th>Frequency</th>
<th>Percentage</th>
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<td>Unemployed</td>
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<td>Skilled non-manual</td>
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<td>Partly skilled</td>
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<td>6.0</td>
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<td>Professional</td>
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<td>17.9</td>
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### Table 4: Participants' referrers

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<tr>
<th>Referrers</th>
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<tr>
<td>GP</td>
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<td>52.2</td>
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<tr>
<td>CPN</td>
<td>18</td>
<td>26.9</td>
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<tr>
<td>Psychiatrist</td>
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<td>4.5</td>
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<tr>
<td>SHO</td>
<td>3</td>
<td>4.5</td>
</tr>
<tr>
<td>Social Worker</td>
<td>1</td>
<td>1.5</td>
</tr>
<tr>
<td>Other</td>
<td>7</td>
<td>10.4</td>
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Table 5: Reasons stated for not attending psychological assessment appointments

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<th>Reason given</th>
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<tr>
<td>Reason unknown as no contact</td>
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<td>42.1</td>
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<tr>
<td>Difficulties resolved</td>
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<td>21.1</td>
</tr>
<tr>
<td>Left area</td>
<td>2</td>
<td>10.5</td>
</tr>
<tr>
<td>Sought other NHS help</td>
<td>2</td>
<td>10.5</td>
</tr>
<tr>
<td>Sought private help</td>
<td>2</td>
<td>10.5</td>
</tr>
<tr>
<td>Unable to attend during office hours</td>
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<td>5.3</td>
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Table 6: Outcomes of psychological assessment

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<th>Outcome</th>
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<tr>
<td>Accepted therapy</td>
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</tr>
<tr>
<td>Declined therapy</td>
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<td>8.4</td>
</tr>
<tr>
<td>Discontinued assessment before completion</td>
<td>2</td>
<td>4.2</td>
</tr>
<tr>
<td>Referred to another service</td>
<td>2</td>
<td>4.2</td>
</tr>
<tr>
<td>Left area</td>
<td>2</td>
<td>4.2</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>2.1</td>
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</table>
APPENDIX 5

CORRESPONDENCE REGARDING

THE FEEDBACK OF RESULTS
Dear

Thank you for providing feedback regarding the results of your Service Related Research Project.

We look forward to receiving a copy of the write-up.

Yours sincerely,

Dr.
Chartered Consultant Clinical Psychologist
Assessing the competency of children and adolescents, adults with learning disabilities and mental health problems and older adults to give informed consent

September 2001
Year 2
Assessing the competency of children and adolescents, adults with learning disabilities and mental health problems and older adults to give informed consent

Introduction

Throughout the twentieth century, the abilities of children and adolescents, and adults with mental health problems to make meaningful treatment decisions has been under increasing scrutiny. Whilst these two groups had previously been thought unable to make meaningful decisions (Weithorn & Campbell, 1982, Appelbaum & Grisso, 1995), attempts have now been made to understand more accurately the extent of their competency to make treatment decisions, and their areas of difficulty.

Bailey and Harbour (1999) outline the current legal position in England and Wales a propos the rights of children to give informed consent. Briefly, from the age of 16 years, young people automatically gain the right to make treatment decisions. Exceptions to this are those with severe disabilities and those who refuse medical or psychiatric treatment. Prior to age 16, children who demonstrate “sufficient understanding and intelligence” can exercise the same rights as adults over their medical and psychiatric treatment (following the first case to be awarded this right, this is usually referred to as “Gillick-competence”).

The Mental Health Act (1983) enables psychiatric assessments and treatments to be conducted without patients’ consent, although there is an automatic right to appeal against this. Assessments of competency are not generally routine, and - as with children and adolescents - difficulties are more likely to arise when treatment is refused. Pearce (1994) notes that a refusal tends to have more significant consequences than compliance with treatment, and has been considered a higher-order of decision-making. When cases are referred to the legal system, courts can over-ride treatment refusals made by members of all of the populations considered in this paper.  

1 It is not possible here to fully detail English law regarding informed consent and young people, this has been done comprehensively and clearly by both Bailey and Harbour (1999) and Shaw (2001).
Focusing on treatment refusal overlooks issues regarding the abilities of compliant patients to give meaningful consent to their treatment. It can seem unethical to assume competency in the face of compliance. Indeed, Pollack and Billick (1999) describe legal action following a patient's consent to voluntary psychiatric hospitalisation whilst incompetent to consent. Several authors describe the difficulty of balancing the protection of those who are unable to give informed consent for themselves whilst ensuring that those who are able to contribute to treatment decisions are involved to the greatest extent possible (e.g. Coyne, 1998, Arscott, Dagnan and Sternfert Kroese, 1998, Kitamura, Tomoda, Tsukada, Tanaka, Kawakami, Mishima & Kitamura, 1998).

It has thus far become evident that informed consent has both ethical and legal implications. The British Psychological Society notes that it also has clinical value, in "working in partnership with children and their parents/carers" (DCP, 2001, p.26). Although early researchers defined consent in differing ways, consensus has emerged that an informed treatment decision requires: understanding of the proposed treatment, its purpose and nature, the reasons why it has been proposed, its risks, benefits and alternatives, including the consequences of not receiving treatment, and the ability to utilise this information in making a decision which is not overly influenced by others (Bailey & Harbour, 1999). It is usually the remit of professionals working with children and adolescents, adults with learning disabilities and mental health problems, and the older adult population to judge their competency to make informed decisions, with recourse to these criteria. Decisions are less often made within the legal system, generally when decisions become particularly problematic.

There is clearly an onus on clinicians to make reliable judgements of patients' competency to give informed consent. This ability has been assessed in varying ways within research studies. This paper will initially describe methods used to measure the competency of children and adolescents, before considering methods used with other vulnerable populations, namely adults with learning disabilities, older adults and adults with mental health problems. Comparisons will be made regarding work in each of these fields.
Assessing the competency of children to give informed consent

In 1982, Weithorn and Campbell published what has become a seminal paper in the study of children’s competency to give informed consent. They devised four vignettes describing diabetes, epilepsy, enuresis and depression, detailing the various treatment options with their expected benefits, risks and side-effects and the likely effects of not receiving treatment. The vignettes were presented to four groups of 24 people, aged 9, 14, 18 and 21. These age ranges were chosen to examine a prior legal decision which, on the basis of Piagetian theory stated that the consent given by 14 year olds “approaches that of the adult” (Weithorn & Campbell, 1982, p.1589). Participants were required to listen to the vignettes and respond to questions regarding their factual understanding and appreciation of the facts in the vignette, stating what treatment choice they would make and their reasons for this.

Results indicated that the 9 year old participants made less competent treatment decisions than adults. Although they were able to indicate choices, they usually considered only 1 or 2 salient factors. One treatment option which they chose more frequently than adults was hospitalisation for depression; the authors suggest that this might relate to increased dependency and deferral to adult judgement and care. Responses given by the 14 year olds differed only from the older age groups in an increased rejection of an anti-epileptic medication which was linked with periodontal problems and hirsutism. These data suggest that there are a broad range of influences upon treatment decisions, which may vary among different age groups, or individuals, and which may lead to different treatment decisions being made.

In this study, treatment decisions were judged by experts. This reflects clinical practice but does not adequately explore the possibility that children’s different preferences may not necessarily be the result of incompetency to consent. Unfortunately the authors do not provide detailed information regarding their scoring criteria and use of prompts during their interviews with children which is problematic as different vignettes presented differing numbers of potential responses. The generalisability of their results
to the ability of, particularly non-white middle-class, children and adolescents to make actual treatment decisions is not known.

Billick, Edwards, Burgert, Serlen and Bruni (1998) attempted to address this issue. They interviewed 25 child psychiatric inpatients (mean age 9.9 years) using a questionnaire adapted for use with adolescent psychiatric inpatients, to assess their ability to give informed consent to psychiatric hospitalisation and treatment. Unfortunately, the authors do not report their scoring procedures or the rationale behind their competency cut-off scores. Those who were identified as competent to give consent had a mean age of 10.1 years, and those found to be incompetent had a mean age of 9.6 years. As the total sample's ages are not reported it is difficult to interpret these figures, especially as the questionnaire had been adapted for use with adolescents and this sample would seem to be rather younger than this. Nonetheless, results are consistent with Weithorn and Campbell's (1982) research, suggesting that the ability to give informed consent develops between the ages of 9 and 14. This study suggests that competency to consent develops rather rapidly from the age of 9 years, although it is difficult to compare the answers of a non-clinical sample responding to hypothetical treatment dilemmas to those given by clinical samples following hospital admission. It will be informative for future research to focus more specifically on the emerging consent competency of young people aged between 9 and 14.

Billick et al report a significant association between reading ability and competency to give informed consent. Fifth-grade reading ability predicted consent competency. In view of their limited sample size, Billick et al appear to over-state the usefulness of this finding, before returning to the importance of life experience, reasoning and judgement abilities in giving informed consent. They state that the Piagetian stage of concrete operational thought is required for informed consent, which is in contrast to Weithorn and Campbell's (1982, p.1590) assertion that formal operational thought is necessary. It is therefore possible that these authors are conceptualising informed consent in slightly different ways but certainly demonstrates some of the difficulty in relating an abstract concept into objective, measurable terms. Billick et al note that the CQ-ChP questionnaire which they used has not been validated since its adaptation for use with
adolescents. Examination of the questions included suggests that it places more emphasis on rote recall and appreciation but less on choice and reasonable outcomes.

In another study, Ondrusek, Abramovitch, Pencharz and Koren (1998) examined the ability of children aged between 5 and 18 years to give informed consent to taking part in a non-therapeutic research study regarding nutrition. Results from their semi-structured interview demonstrated that understanding of straightforward procedural information did not relate to age, but that understanding of the study’s purpose, potential risks and benefits and right to withdraw improved with age. The authors identify a ‘turning-point’ in the acquisition of such knowledge at around age 9. This idea seems consistent with the relatively small age difference between participants identified by Billick et al as competent versus incompetent, although Billick et al’s data suggest that the turning point occurs slightly later. It is possible that this could be an artefact of a clinical sample. Ondrusek et al’s study could usefully be replicated with a larger sample, as only 18 participants were included. It might also be useful to consider differences between consenting to research as opposed to medical or psychiatric treatment.

Each of these studies employed small samples, which compromises the generalisability of their results. This could be addressed in future research. As no authors provided detailed information regarding their inclusion and exclusion criteria, it would appear that specific subgroups of children, for example those with learning disabilities or communication disorders, have been excluded. In addition, Billick et al and Ondrusek et al did not adequately control for the amount of information given to children prior to making assessments of their competency, a factor which clearly undermines the results obtained. Lastly, Reder and Fitzpatrick (1998, p.106) list additional methods of determining children’s competency. These include “asking questions...talking about personal hopes and fears...seeking reassurance about support...showing a reasonable anxiety about risk and discomfort, and a reasonable hope of benefit”. Clearly, the objective assessment of such areas will pose something of a challenge.
Literature Review

Assessing the competency of people with learning disabilities to give informed consent

Morris, Niederbuhl and Mahr (1993) adapted Weithorn and Campbell’s work, making it relevant to adults with learning disabilities. They devised vignettes regarding behavioural programmes, psychotropic medication and hernia surgery. Groups of 15 individuals with a mild, moderate or no learning disability then responded to their, and therefore non-random, choice of 2 vignettes. Structured interviews were blind-rated, and inter-rater reliability was good. 6 of the 15 adults with mild learning disabilities and 1 with a moderate learning disability were judged competent to give informed consent. Results indicated particular difficulty in understanding rights, e.g. to make a free choice or to refuse treatment, among people with learning disabilities.

Unfortunately, this study had a small sample in each group. The authors do not address the impact on participants of their decision to word vignettes in the second-person which might seem distressing or confusing, and unlikely to facilitate participants’ separation of their own experiences from the fictional accounts. It is important to note that the relationship between results from questionnaires like this and real-life treatment decisions has not been established and researchers could profitably consider the influence of healthcare staff working with individuals who make treatment decisions. Lastly, it is questionable how representative this sample is, as some participants were recruited from a ‘Multiply Disabled unit’ and others from a ‘facility unit for individuals with severe maladaptive behaviours’. No participants had significant mental health problems.

Arscott, Dagnan and Stenfert Kroese (1998) developed Morris et al’s assessment tool, simplifying the language used, introducing line drawings, replacing American terminology, putting vignettes into the 3rd person and adjusting scoring guidelines to enable more sensitive judgements to be recorded. They administered it to 40 adults with learning disabilities, 26 of whom were scored as competent to give informed consent to at least 1 vignette. As before, questions regarding rights appeared to be the most challenging. The high inter-rater reliability obtained suggested that the adapted
scoring criteria were reliable. Questions posed by this study include the ongoing need for validity checks with such tools, and the challenges facing clinicians working with those with severe learning difficulties, concurrent mental health problems or communication difficulties, and/or those who are judged wholly or partially incompetent to give informed consent.

Assessing the competency of older adults to give informed consent

Whilst children have been thought unlikely to be competent to give informed consent due to their developing cognitive ability, at the other end of the lifecycle, the competency of older adults has been questioned due to their increased frequency of cognitive dysfunction and the view that their faculties are diminishing. Tymchuk, Ouslander, Rahbar and Fitten (1988) also suggest that their competency may be compromised by sensory impairment and dependent relationships within institutions. These authors employed the vignette approach which has been employed in work with adults with learning disabilities and children, to examine the ability of older adults to give informed consent to medical treatment decisions. Tymchuk et al devised vignettes which they varied according to their complexity of presentation and degree of risk, i.e. aortic valve replacement and carotid endarterectomy versus flu vaccination and sleeping pills.

70 residents of a long-term care unit participated in this study. Following presentation of the vignettes, their comprehension and decision-making were rated. The lowest mean competency score was for the aortic valve vignette in its standard presentation, this was 56%. With simplified presentation, the flu vignette obtained a much higher competency score of 75%. The authors state that the presentation style had more impact upon the higher risk scenarios, yet it also affected competency as assessed by the sleeping pill vignette. Further research is required with a broader range of vignettes before such conclusions can reliably be made. The authors state that testing time varied between 2½ and 3 hours per participant, which is a long time for any participant without a break. It would be good to reduce this in any replications of this study.
Generalisability is hampered by the fact that all participants were recruited from one care unit; furthermore as this was Jewish, it may be subject to cultural bias.

Stanley, Guido, Stanley and Shortell (1984) used vignettes to assess the competency of older adults to give informed consent to participation in research. Like Tymchuk et al, they varied their six vignettes according to the level of risk posed by the, hypothetical, studies. They then compared the performance of medical outpatients aged between 22 and 41 with those aged above 62 on a questionnaire which considered reasonableness of decision, quality of reasoning and comprehension of consent information. The results indicated a significant difference between comprehension of consent information, favouring the younger sample, and a non-significant trend for the older sample to under-achieve on the reasoning test. The older sample were significantly more likely to state that they would participate in one higher-risk research study. Although this study suggests that the older adult population may demonstrate difficulties in giving informed consent to participation in research, the authors do not address the influence of cohort effects. It is possible that the commitment to participation in research evident within this study was a result of increased compliance and respect for the importance of research rather than impaired competency to consent. It would have been informative to explore the two groups' reasons for participation in research. In addition, it is possible that, as has been suggested with young people, different decisions are the result of legitimate preferences rather than impaired competency.

Assessing the competency of people with mental health problems to give informed consent

In 1981, Appelbaum, Mirkin and Bateman published one of the first empirical investigations into the capacity of psychiatric patients to give informed consent. They devised a 15-item questionnaire, which was administered to 50 psychiatric in-patients. This assessed appreciation of psychiatric illness, awareness of the nature of hospitalisation and the reason behind its recommendation, knowledge of legal rights, ability to decide whether to co-operate with treatment, and ability to communicate
with staff. Although reliability and validity data regarding the questionnaire are not available, only half of the participants were aware of their legal rights and only half acknowledged their illness and need for in-patient treatment. Unfortunately, no control was exercised over the procedures via which patients were informed of their legal rights. It would appear that there are no straightforward means of resolving issues regarding insight, the recognition of mental illness and the need for treatment within informed consent work with this client group, where the nature of mental illness dictates that some patients will not recognise the presence of severity of their condition.

The MacArthur treatment competence studies (Appelbaum & Grisso, 1995; Grisso, Appelbaum, Mulvey & Fletcher, 1995, & Grisso & Appelbaum, 1995) offer a thorough review of informed consent from a historical, legal and conceptual standpoint which is followed by descriptions of the development and standardisation of the MacArthur Treatment Competence Research instruments. Unlike Appelbaum et al’s (1981) study, Appelbaum and Grisso (1995) acknowledge the importance of investigating the provision of information to patients before making assessments of their competency. They also consider difficulties in research with this client group, including the heterogeneity of the mentally ill population, the fluctuating effects of mental illness upon consent competency, issues regarding sampling which tend to lead to the exclusion of more severely ill patients and the lack of standardised measures of consent competency.

Participants in these studies were recruited from three different geographical locations and comprised different diagnostic groups. Within mental health, these were schizophrenia and major depression. Schizophrenia was chosen due to its severity and known impact on cognitive processes, and depression due to its high prevalence. These groups were contrasted with community control groups and patients with ischemic heart disease, which was chosen to match the mental illness groups in terms of chronicity, ongoing need for drug treatment and high incidence of hospitalisation. All groups were matched according to such variables as age, gender and socio-economic
status. Sample sizes approached 100 for each group, which is clearly superior to the studies reviewed thus far.

Grisso et al (1995) outline each competent of the MacArthur assessment. ‘Understanding Treatment Disclosures’ involves the standardised presentation of relevant information and assesses participants’ paraphrased recall and recognition memory. ‘Perceptions of Disorder’ examines acknowledgement of illness and recognition of the need for treatment. This is developed beyond the work of Appelbaum et al (1981) by exploring the underlying reasons for non-acknowledgement, such as religious and cultural beliefs, past experience or delusions. Unfortunately, their exploration of the likely benefit of treatment is rather mainstream and narrow in its focus, and does not appear to take account of alternative views, as sometimes expressed by service users and advocacy groups. However, validity is increased by cross-reference from scores on this subtest to those obtained from symptom rating scales. ‘Thinking Rationally about Treatment’ measures such things as information-seeking, considering general and personal consequences, thinking about a range of alternatives, making logical inferences and judging probabilities. The last aspect of the assessment, ‘Expressing a Choice’, is measured with only 1 item, which does not seem sufficiently complex. Nowhere does the assessment measure external influences on the decision-making outcome or process.

The authors present detailed information regarding the psychometric properties of this assessment. They address problems with inter-rater reliability and internal consistency by omitting items and re-working scoring criteria in revisions of the assessment. When the assessment was administered to the groups outlined above, the schizophrenia and depression groups demonstrated an increased frequency of incompetency to consent. Despite this apparently gloomy statistic, approximately three quarters of the depression group and almost half of the schizophrenia group gave adequate consent according to these measures. This certainly contrasts with the early opinion that mental illness meant an inevitable inability to give meaningful consent and demonstrates the importance of such research. Grisso et al’s statement that competency figures were boosted following repeated administration of treatment information suggests that such procedures can be
usefully incorporated into clinical practice. Closer examination of results suggested that individuals in the two mental illness patient groups showed significant variation in their competency. Even though the schizophrenia group appeared to have the most difficulty, the majority of the group did not perform more poorly than individuals in the other groups. Instead, the group’s performance was decreased by a significant minority. The psychiatric rating scales administered suggested that this minority also demonstrated the most severe symptomatology, especially pertaining to thought disturbance. They were not distinguishable according to any demographic factors. In their conclusion, Grisso et al note that some of the most severely ill patients were excluded from the study, as they were unable to give informed consent to participate. These results would therefore seem to over-estimate the ability of the psychiatric population as a whole to give informed consent to treatment.

Despite the considerable attention to conceptualising informed consent and rigorous methodology employed in the MacArthur studies, Pollack and Billick (1999) note that the assessment is too lengthy to be useful in everyday clinical practice. In addition, they state that the degree of standardisation makes it difficult to adapt to different cases and suggest that the scoring procedures require more attention.

Despite these reservations, Appelbaum, Grisso, Frank, O’Donnell and Kupfer (1999) used the MacArthur Competence Assessment Tool devised for clinical research to examine the competency of women suffering from depression. Although this was an out-patient sample, which contrasts with other research, its generalisability is uncertain since the 26 participants were already enrolled in a psychotherapy research study and may therefore demonstrate above-average experience, interest or motivation in such research. This could be reflected in the finding that all participants obtained a high level of performance on the understanding, appreciation and reasoning assessment scales. There was some confusion regarding the fact that allocation to treatment was to be random, rather than based on individual need. Although the authors underplay this result, it has important ethical implications, and it would be good to replicate this study with a larger sample, and ensure that such misunderstandings are corrected. Although the authors praise the ease of administration of this assessment tool, the power
imbalance between the two scorers raises issues regarding their discussion of results and the reliability of their decisions.

In a similar study, Wirshing, Wirshing, Marder, Liberman and Mintz (1998) assessed the ability of 49 schizophrenic patients to give informed consent to participation in clinical research. This was measured using a specifically-designed survey which was repeated at a 1-week follow-up. A median score of 80% was obtained following the first administration. Repeated administration facilitated the attainment of 100% correct responses from increasing numbers of participants. This provides further support for Grisso and Appelbaum's (1995) report that repeated presentation is useful. Results at follow-up indicated an improvement since the first trial; this too is encouraging, suggesting that once processed, information is retained. The overall success rate is comparable to that obtained in the MacArthur treatment studies, which could be seen as suggesting that competency to consent may be relatively stable across different domains, i.e. treatment and research.

This study is subject to the same sampling bias - and exclusion of the most severely ill patients - as many others within this field. Despite this, the authors note that participants' competency varied widely. They included an open-ended question asking how participants would feel if proxy consent were required and it is regrettable that they do not report results to this. Rather than focus on the psychometric properties of assessment tools, Wirshing et al conclude with the intention to adopt a more practical position, developing procedures to maximise patients' competency.

Kitamura, Tomoda, Tsukada, Tanaka, Kawakami, Mishima and Kitamura (1998) discuss informed consent within Japanese culture and law, comparing it to the American literature. They highlight the fact that competency is not static, and therefore requires routine, repeated independent assessment. They also consider the difficulty of relating research into clinical practice, for example while research requires standardised information to be given to enhance validity and reliability, patients with different illnesses, treatment recommendations and information processing styles will benefit from a more individualised approach. Kitamura et al describe the development of their
assessment tool which attempted to answer the criticisms given above. This is readily adaptable for use with individuals, and assesses the information given to them, thereby focusing on the interplay between treatment information and consent competency. As in the MacArthur treatment studies, the performance of patients on medical wards was superior to that of those on psychiatric wards. However, the difference was rather small, with 19 of 25 psychiatric patients being defined as competent and 21 of 23 medical patients. The authors do not fully explore this finding in relation to the observation that psychiatric patients tended to receive less information. It is unfortunate that this sample is very small and no checks were made of physicians’ reports regarding the treatment information given to patients. The authors also raise the question of what measures should be taken with participants who are partially able to give consent.

Pollack and Billick (1999) describe the Hopkins Competency Assessment Test (HCAT) which was devised by Janofsky (1992, cited in Pollack & Billick, 1999, p.306) for use with medical and psychiatric patients. Similar to the work which has been conducted with adults with learning disabilities and children, it presents the necessary information to give informed consent and assesses comprehension. Pollack and Billick applaud this instrument, due to high inter-rater reliability, correlations with a forensic psychiatrists’ competency assessment and eradication of the influence of reading ability via oral presentation. They do not comment on its narrow focus, overlooking aspects of consent such as decision-making and reasoning but conclude that it provides a useful screening measure.

It was employed as such by Jones, Jayaram, Samuels and Robinson (1998) with a sample of 43 in-patients with a chronic mental illness. 84% of these were found competent to give informed consent according to the HCAT, a figure which is comparable to those obtained in other studies. This would seem to provide further support for the utility of the HCAT. Jones et al comment that the minority of participants found unable to consent did not appear incompetent; this demonstrates the need for routine screening. Echoing Billick et al’s relation of reading ability to competency in children, Jones et al compared competency as defined by the HCAT
with results on the Mini Mental State Examination (MMSE) and length of schooling. They conclude that reduced performance on the MMSE and fewer than 12 years education tended to indicate difficulty with the HCAT. Although Jones et al note that the HCAT might reflect more advanced educational ability, they suggest that clinicians be alert to the possibility of incompetency to consent among patients meeting these criteria.

Conclusions

The literature reviewed has suggested that clinicians working with children and adolescents, adults with learning disabilities and mental health problems and the older adult population should be always alert to the possibility of impaired capacity to give informed consent. It is becoming important to develop clear guidelines regarding both the degree of competency which individuals need to demonstrate and procedures to follow with those who have demonstrated incomplete competency.

Assessing competency to give informed consent is not a straightforward task. Pollack and Billick (1999) state that although questionnaires tend to be quick, easy to administer and inexpensive, they note that they do not account for change across time. It is also important for further work to establish the validity of each of the measures reviewed. Despite this, work within the mental health population appears to be reaching a consensus regarding consent competency, which suggests that such assessments could, over time, become useful adjuncts to clinical judgement.

Related to the degree of competency required to give informed consent to different procedures is consideration of the consent given by the majority of the normal population which is rarely questioned because they are legally able to give their own consent. Further research into this area can suggest the degree of competency which is required for valid consent, and seems likely to identify a preference for simplified procedures, as suggested by Tymchuk et al with older adults.
There are many questions within the field of competency to give informed consent, which could be answered by future research. The needs of populations not yet considered could be viewed as a priority; despite the challenges posed, this includes the more severely mentally ill and those with dual or multiple diagnoses, e.g. learning disabilities and mental health problems, who have so far been excluded from research. There has also been insufficient attention paid to the assessment of outcome judgements. These have tended to be decided by expert opinion but could be usefully informed by service user groups.
References


<table>
<thead>
<tr>
<th>Research Skill or Experience</th>
<th>Description of how research skill/ experience acquired</th>
<th>Date acquired</th>
</tr>
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<tr>
<td>Conduct a literature search</td>
<td>Many and varied, using Medline and Psycit databases. ScienceDirect used to search journals and access articles online. Able to use, combine and exclude keywords and vary search factors including population.</td>
<td>Throughout course</td>
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<tr>
<td>Critically review the literature</td>
<td>Literature review regarding means of assessing ability to give informed consent</td>
<td>Jul 01</td>
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<td>Formulate a specific research question</td>
<td>After discussion with field and university supervisors decided to conduct service-related research project comparing referral letters and psychologists' assessment reports. Discussed issues with university supervisors and clinicians regarding informed consent among children, and planned a major research project to explore this area (later abandoned). After discussion with field and university supervisors decided to conduct major research project investigating Harvey's (2002) cognitive model of insomnia with older adults with mental health problems</td>
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<td>Write a brief research proposal</td>
<td>As above, service-related project As above, informed consent project As above, major research project</td>
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<tr>
<td>Write a detailed research proposal</td>
<td>As above, service-related project As above, informed consent project</td>
<td>Nov 99 Jan 01</td>
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<tr>
<td>Obtain appropriate supervision/collaboration for research</td>
<td>Accessed support of university tutors and placement supervisor to become research supervisors for service-related research project Obtained support from university tutors and child inpatient unit for informed consent project Obtained support of university tutors, placement supervisor and clinicians for major research project</td>
<td>Oct 99 Dec 00 Feb 03</td>
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<tr>
<td>Write a participant information sheet and consent form</td>
<td>Written for first major research project (later abandoned) regarding informed consent Written for major research project regarding insomnia</td>
<td>Aug 01 Feb 03</td>
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<tr>
<td>Judge ethical issues in research and amend plans accordingly</td>
<td>Applications made to research ethics committees: regarding informed consent project regarding insomnia project Amendments made to insomnia project</td>
<td>Sep 01 Feb 03 March 03</td>
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| Obtain approval from a research ethics committee | Approval obtained from East Surrey Local Research Ethics Committee regarding insomnia (major) research project  
Approval obtained from university research ethics committee regarding insomnia project | March 03  
July 03 |
|---|---|---|
| Collect data from research participants | Completed via interview for qualitative project regarding trainees’ experiences of self-efficacy whilst undertaking clinical psychology training  
Completed via questionnaires from older adults attending Redhill and Epsom community mental health services for older people | March 01  
July - Sep 03 |
| Set up a data file | Undertaken using SPSS software to analyse data for service-related research  
Undertaken, again with SPSS, to analyse data for major research | March 00  
Sep 03 |
| Analyse quantitative data | See service-related project and major research project | May 00  
Sep 03 |
| Analyse qualitative data | Qualitative project successfully conducted regarding trainees’ experiences of clinical psychology training (group project) using Interpretative Phenomenological Analysis (IPA) | April 01 |
| Summarise results in figures/graphs | See service-related project and major research project | Jun 00  
Sep 03 |
| Interpret results from data analysis | See service-related project and major research project | Jun 00  
Sep 03 |
| Present research findings/plans to an audience | Process and outcome of service-related research project presented to the department where it was conducted, the course team and first year clinical psychology trainees  
Plan for informed consent major research project presented to course team and second year clinical psychology trainees  
Plan for major research project presented to the services where it was conducted  
Results of major research presented to the services where it was conducted | Jun 00  
Oct 00  
Oct 01  
May & Jul 03  
Oct 03 |
| Produce a written report on a research project | See service-related project and major research project | Jun 00  
Oct 03 |
| Defend research project at oral examination | Viva voce exam | Nov 03 |
| Apply research | The following papers were influential in my clinical work:  
| findings to clinical practice | Understanding and treating obsessive-compulsive disorder. *Behaviour research and therapy*, 37, S 29-52.  
Major Research Project

Does Harvey’s (2002) cognitive model of insomnia explain sleep disturbance among older adults with mental health problems?

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Year 3
Abstract

Previous research has identified an increased incidence of insomnia among older adults, and among adults with mental health difficulties. Harvey’s (2002) cognitive model of insomnia asserts that insomnia will be predicted by negative cognitive activity, dysfunctional beliefs about sleep and counter-productive safety behaviours. The applicability of the model to the insomnia experiences of older adults with mental health difficulties was examined using self-report questionnaires. Correlational analyses demonstrated significant relationships between each of the variables investigated, which were consistent with the model. Implications for Harvey’s model, including the observed influence of worry as an important safety behaviour and the importance of considering the roles of physical tension and individual beliefs about sleep, and treatment recommendations are discussed.
Introduction

Overview

Insomnia is a widespread problem (Espie, Inglis, Harvey & Tessier, 2000; Fichten, Libman, Creti, Amsel, Tagalakis & Brender, 1998), which has been associated with many potentially harmful consequences (Morin, 1993; Roth & Ancoli-Israel, 1999). It is more common among older adults (Mellinger, Balter & Uhlenhuth, 1985; Ancoli-Israel & Roth, 1999) and people with mental health difficulties (Morin, 1993; Morin & Ware, 1996; Ohayon, Caulet & Lemoine, 1998, Harvey, 2002). Behavioural (Morin & Azrin, 1988; Morgan & Gledhill, 1991) and cognitive behavioural (Morin, Kowatch, Barry & Walton, 1993; Fichten et al., 2001) approaches have been used to attempt to explain insomnia and guide treatment planning. Harvey (2002) proposed a cognitive model of insomnia which considers the roles of negatively toned cognitive activity, arousal and distress, selective attention and monitoring, distorted perceptions of deficit, dysfunctional beliefs about sleep and safety behaviours in the maintenance of insomnia. There is some available which supports this model, but many questions for further research remain.

Identifying insomnia

Although insomnia can be defined as a “difficulty in initiating or maintaining sleep” (Espie, Inglis, Harvey & Tessier, 2000, p141), a more detailed set of diagnostic criteria tends to be required in clinical practice. The Diagnostic and Statistical Manual of Mental Disorders - fourth edition (DSM-IV; American Psychiatric Association, 1994) criteria (Appendix A) are the most frequently used diagnostic tool in both research and clinical practice. This classification system requires symptoms – difficulty initiating or maintaining sleep - to last for longer than one month, to cause distress or impaired daytime functioning, and to occur independently of other sleep disorders, psychological disturbances, medical conditions or substance use. It may concern either sleep initiation or maintenance, known as sleep-onset insomnia and sleep-maintenance insomnia, respectively.
As with other psychological disturbances, definitions of insomnia must enable the differentiation of those afflicted from healthy controls in order to identify patients requiring treatment and potential research participants. They can also form a first step in assessing the severity of disturbance. DSM-IV does not define objective criteria for poor sleep or the associated distress, and does not specify how often someone must suffer with poor sleep for a diagnosis of insomnia to be made. Morin (1993) provides further guidance, suggesting that disturbed sleep on 3 or 4 nights per week should be classified as clinically significant. He suggests that sleep-onset insomnia requires a sleep-onset latency (time spent getting to sleep) greater than half an hour and sleep maintenance insomnia requires more than half an hour spent awake during the night. Where insomnia presents both disturbed sleep initiation and maintenance, he advocates consideration of a 'sleep efficiency' below 85% (time spent asleep divided by time spent in bed). This criterion has been used in research studies (e.g. Wicklow & Espie, 2000).

Other authors suggest that the distress associated with insomnia is its defining feature. Stepanski, Koskorek, Zorick, Glinn, Roehrs and Roth (1989) did not find significant differences in measures of sleep between those attending a sleep clinic and non-treatment seeking insomniacs recruited from the general population. However, the groups could be differentiated via their results on psychometric measures; those attending sleep clinics reported increased psychopathology, particularly depression. Although Stepanski et al did not control for or measure the direction of effects between insomnia and depression, participants tended to report that their mood disturbances were secondary to their insomnia.

DSM-IV's requirement that a diagnosis of insomnia must be independent of other psychological and medical disorders also poses a diagnostic challenge for clinical psychologists. Diagnosis must distinguish insomnia from sleep disturbances due to psychological disorders, e.g. depression and anxiety. It must also distinguish distress due to insomnia (a necessary diagnostic criteria) from that caused by psychological disturbances. Morgan and Gledhill (1991) distinguish between primary and secondary insomnia, defining that which occurs in the absence of medical or psychological
disturbances as primary insomnia, and secondary insomnia as that which is associated with psychological or medical ill-health. These authors take the stance that both warrant treatment, as it cannot be assumed that treatment for 'underlying problems' will resolve secondary insomnias.

Although there are clear difficulties in relying on DSM-IV criteria for a valid and reliable diagnosis of either primary or secondary insomnia, Harvey (2002, p.870) describes an alternative set of criteria, published by the International Classification of Sleep Disorders - Revised (ICSD-R; American Sleep Disorders Association, 1997), as "unwieldy and under-researched". This system includes 38 different subtypes of insomnia, but lacks clear inclusion or exclusion criteria, and assessment procedures. As the DSM-IV criteria have been more commonly used in psychological research and are the most relevant to this study, ICSD-R criteria will not be discussed in any more depth here.

Prevalence of insomnia

Given the problems outlined above, it is not surprising that the reported prevalence of insomnia varies according to the definition adopted, the population studied and the mode of measurement. It is common for authors to report data regarding both occasional and chronic insomnia. Espie et al. (2000) suggest that whilst up to 30 per cent of adults may experience intermittent or occasional bouts of insomnia, the prevalence of clinically significant insomnia is between 10 and 15 per cent. Chevalier et al. (1999) report a 22% prevalence of "severe insomnia" among adults aged 18 and above in the UK. Fichten, Libman, Creti, Amsel, Tagalakis and Brender (1998) state that between 30 and 40 per cent of the general population may experience occasional difficulties with sleep. However, they report a significant increase in the prevalence of insomnia among older adults, with between 50 and 60 per cent of adults aged over 60 experiencing occasional difficulties, and between 10 and 35 per cent of adults aged over 65 experiencing chronic insomnia.
This increase in insomnia among older adults is widely reported in literature from both the UK and the USA (Espie, Inglis, Harvey & Tessier, 2000; Harvey, 2002; Morin & Azrin, 1988; Regenstein, 1980; Voderholzer & Berger, 1999). For example, Ancoli-Israel and Roth (1999) report data obtained from a general population telephone survey of 1000 American adults, and state that 9 per cent reported suffering from chronic insomnia. This figure increased to 20 per cent among those aged over 65. Similarly, the sample described by Mellinger, Balter and Uhlenhuth (1985) demonstrates increased insomnia with increasing age; 14 per cent of 18 to 34 year olds and 25 per cent of adults aged 65 to 79 reported being "troubled a lot" by insomnia.

Sleep in older adults

There are various explanations for the increased prevalence of insomnia among older adults. The first of these is summarised by Morgan and Gledhill (1991) and concerns physiological changes. They state that sleep duration per night decreases with age, and is accompanied by an increase in the duration of light sleep (known as Stages 1 and 2) and a decrease in the duration of deep sleep (stages 3 and 4) compared to younger people. The effect of this changing pattern of light versus deep sleep is that sleep is more readily interrupted by both internal and external stimuli. Morgan and Gledhill also state that the relationship between day- and night-time and the biological clock weakens with age, which increases the likelihood of sleep during the daytime and wakeful periods at night. They also identify additional factors which are likely to impact upon the reduced quality of sleep in older adults, including increased incidences of nocturia (the need to urinate during the night), medical problems, discomfort or pain and/or medication as compared to younger adults. The association between poor physical health and insomnia among older adults has been established empirically by Morgan and Clarke (1997) and Morgan (2003). Some of these factors (e.g. nocturia) go some way towards explaining the fact that the insomnia experienced by older adults tends to be characterised by difficulties maintaining, rather than, initiating sleep (Edinger, Hoelscher, Marsh, Lipper & Ionescu-Pioggia, 1992; Morin, 1993).
The second line of explanation for the increased insomnia observed among older adults concerns behavioural factors. Morin, Stone, Trinkle, Mercer and Remsberg (1993) describe the major lifestyle changes experienced by older adults at or after retirement. The loss or reduction of occupational demands and structured routines has been associated with the development of irregular sleep schedules and spending excessive amounts of time resting or asleep. Excessive sleep or rest has been demonstrated to be counter-productive in resolving sleep difficulties (Morin, Kowatch, Barry & Walton, 1993). Similarly, a direct relationship has been identified between low activity levels and insomnia in older adults (Morgan & Clarke, 1997; Morgan, 2003). Morgan and Gledhill (1991) identify psychosocial and environmental influences on the sleep of older adults: bereavement, stress and worry, inadequate heating, and old, uncomfortable bedroom furnishings. Amongst this client group, depressed mood has not only been related to insomnia (Morgan & Clarke, 1997; Morgan, 2003) but to increased treatment attrition rates (Morgan, Thompson, Dixon, Tomeny & Mathers, 2003).

Morin and Gramling (1989) investigated the extent to which insomnia in older adults (aged 60 years and above) indicates psychological disturbance, as opposed to being an inevitable consequence of the normal ageing process. They recruited 42 treatment-seeking poor sleepers and 30 control participants. As expected, poor sleepers reported longer sleep-onset latency and increased difficulty maintaining sleep. They scored significantly higher on the Beck Depression and State-Trait Anxiety Inventories, and demonstrated less realistic beliefs about sleep by over-estimating the amount of sleep required. However, daytime napping, exercise, physical illnesses, medication usage and sleep hygiene did not differentiate the two groups. Morin and Gramling argue that the distress and anxiety, and differing beliefs about sleep observed among poor sleepers as compared to control participants imply that insomnia among older adults is not an inevitable consequence of the normal ageing process, as might be implied from the evidence regarding physiological changes. Instead, they cite the increased distress and dysfunctional beliefs of insomniacs to argue that insomnia can represent a significant

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1 Sleep hygiene (defined in more detail on page 175) refers to a range of sleep-promoting behaviours.
source of psychological distress which warrants the development and provision of effective treatment(s).

The impact of insomnia

The importance of establishing effective treatments for insomnia can be highlighted by examining its correlates and potential consequences, which can be physical, emotional and behavioural. In the telephone survey described above, Roth and Ancoli-Israel (1999) found that participants who reported suffering with chronic insomnia reported less favourable results on a range of measures, including reduced quality of life and ability to accomplish tasks or enjoy relationships, impaired concentration, increased feelings of fatigue and irritation, and increased risk of road traffic accidents due to tiredness. Chevalier et al. (1999) report an increased use of healthcare services, including hospital admissions, tests, medical consultation and increased drug consumption among adults with "severe insomnia". Among older adults, Morin (1993) reports that insomnia, accompanied by behavioural disturbances such as night-time wandering, is associated with a significant increase in the likelihood of requiring nursing-home placement. Although these results appear alarming, it is important to note that Roth and Ancoli-Israel did not control for age or medical and/or psychiatric diagnoses. They did not use objective evidence to support participants' self-reports and the data do not allow causal effects to be assumed.

Insomnia and mental health

In addition to the variables listed above, insomnia has also been frequently related to psychiatric disturbance. Coleman (1983, cited in Buysse et al., 1989) states that approximately a third of sleep clinic patients demonstrate insomnia associated with a psychiatric diagnosis, often depression or anxiety. In accordance with the results of Morin and Gramling described above, Mellinger et al. (1985) report survey data, describing increased depressive and anxious symptomatology amongst self-reported insomniacs. Morin (1993) further differentiates these, suggesting that anxiety most
frequently relates to sleep-onset insomnia, and depression to sleep-maintenance insomnia.

Whilst Morin and Ware (1996) report that observed estimates of comorbidity of insomnia and mental health problems have varied between 12 and 71 per cent in adults, this relationship has received less attention among the older adult population. They suggest that comorbidity in this population might be confounded by the aforementioned increased incidence of medical conditions and/or treatments which can affect sleep and/or mental health. Voderholzer and Berger (1999) suggest that nocturia, chronic pain, cardiac and respiratory disorders, and secondary depression resulting from any of these conditions are common causes of sleep disturbance among the older adult population.

Ohayon, Cautel and Lemoine's (1998) report of sleep and mental health disorders in a general population survey of 5622 adults demonstrates several significant findings. Firstly, their large sample size enables them to consider subgroups within this population; for example, they describe more severe daytime disturbance and lethargy, increased nocturnal awakenings and increased duration of insomnia among participants with depression. Secondly, they note that as there is no objective means of distinguishing between primary insomnia which has contributed to a mental health disorder and secondary insomnia which has arisen as a result of a mental health disorder, this distinction depends predominantly upon participants' own explanations of their difficulties. This has clear consequences for the likely referrals sought by sufferers, and requires that professionals working in both sleep and mental health services have some knowledge of each other's work. Ohayon et al also note that younger participants tended to suffer from insomnia as a primary disorder and anxiety as a secondary disorder, but that this pattern was reversed among older participants. They use this observation to suggest that over time, insomnia adopts the role of a secondary disorder, while comorbid psychopathology exerts more influence on day-to-day functioning, and would therefore be the logical focus of treatment.
This suggestion is supported by Harvey’s conclusion to her literature review, where she states that insomnia is “unlikely to be merely consequential...rather is a risk factor for and may even be causal” in the development of mental health problems (Harvey, 2002, p870). Stepanski et al. (1989) propose two hypotheses to explain the increased incidence of depression among their sample of treatment-seeking insomniacs. Firstly, they suggest that these individuals may be overly sensitive to the effects of poor sleep. Alternatively, their need for treatment might relate to underlying psychological disturbance, which individuals have attributed to their sleep difficulty. In accordance with either of these hypotheses, Fichten et al. (2001) report that many insomniacs do not experience clinically significant sleep deprivation or daytime sleepiness, which suggests that the reported correlates of insomnia are not simply the result of extreme tiredness. This lack of clinically significant sleep deprivation parallels earlier comments regarding the role of distress, rather than objective measures of sleep, as an important distinguishing feature in the diagnosis of insomnia.

Measurement of insomnia

There are various means of measuring insomnia, each of which can influence the results obtained. Psychological research has most frequently used self-report measures, either sleep diaries or questionnaires. Fichten et al. (2001) argue that this is more appropriate than objective measurement due to the particular importance of personal experience. Chesson et al. (1999) note that daily sleep logs are common in outcome literature, but can be very time-consuming to complete, which poses a threat to compliance with research. Their convergent validity and reliability have also been questioned (Lacks & Morin, 1992; Wicklow & Espie, 2000); nonetheless due to their widespread use enabling comparison with other research studies, the ability of sleep logs to provide valuable information should not be overlooked.

It is widely accepted that the retrospective recording of cognitions, behaviours, or sleep may be subject to memory effects. However, Fichten et al. (2001) warn that there may also be bias when measures are completed during the daytime, due to a reduction of the arousal and distress associated with sleep disturbance. Wicklow and Espie
(2000) state that attempts to avoid self-report measures, by recording sleep-related behaviour in vivo, have tended to be rather intrusive. Objective methods of recording brain activity to determine duration and quality of sleep are referred to as polysomnography (PSG) methods and have traditionally required participants to sleep in laboratories. As Lacks and Morin (1992) state, laboratory effects on sleep and sleep-related behaviour are difficult to determine. More recent attempts to measure sleep objectively have utilised wrist-worn ‘actigraphes’, which measure participants’ movements to estimate the likelihood of sleep versus wakefulness. Wicklow and Espie (2000) report that these reduce the physical intrusion of PSG and appear to provide reliable measures.

**Treatment of insomnia**

**Pharmacological**

Medication to assist sleep is available both on prescription and ‘over-the-counter’, and represents the most readily accessible remedy for insomnia. Forty per cent of the insomniac sample in the population survey described by Roth and Ancoli-Israel (1999) reported that they had used either ‘over-the-counter’ medication or alcohol to help them sleep. Twenty-one per cent had taken prescription sleep medication, and almost 40 per cent had taken prescription medication other than sleep medication to help them sleep. Morin, Kowatch, Barry and Walton (1993) state that medication represents the most common form of treatment for insomnia, particularly among older adults.

However, Chesson et al. (1999) describe the side-effects of pharmacological treatments. These include tolerance effects, and ‘rebound insomnia’ on cessation. Morin and Azrin (1988) warn that the reduced metabolic functioning of older adults places them at particular risk of adverse effects. Researchers have identified a list of potential effects of sleep medication, including: impaired cognitive functioning, memory and concentration, problems with co-ordination and an increased risk of falls, drowsiness, confusion and mood disturbances, and an increased risk of toxic drug
interactions (Morin, Kowatch, Barry & Walton, 1993; Morgan & Gledhill, 1991; Edinger & Wohlgemuth, 1999).

Behavioural

Whilst pharmacological treatments have been demonstrated to have clear benefit in the short-term management of insomnia, Edinger and Wohlgemuth (1999) point out that they do not address the processes responsible for its onset or maintenance. They suggest that behavioural factors, including sleep habits and conditioned emotional responses, are important. Morgan and Gledhill (1991) summarise three treatment approaches derived from the behavioural literature. Firstly, providing education about sleep can help insomniacs to set more realistic expectations about sleep and identify unhelpful strategies such as napping and ‘recovery nights’, whereby sufferers disrupt their sleep routine by over-sleeping to compensate for a period of poor sleep. Secondly, ‘sleep hygiene’ refers to a range of sleep-relevant behaviour. Interventions in this area include reducing alcohol and caffeine intake, increasing exercise, eliminating day-time naps and establishing effective ‘wind-down’ evening routines. Finally, ‘stimulus control’ techniques address the unhelpful association which can develop in insomnia between bedtime and/or the bedroom and wakefulness or worry. Specific bedroom routines are prescribed, for example only going to bed when tired, and not staying in bed when unable to sleep.

Morin and Azrin (1988) demonstrated the efficacy of stimulus control techniques in a study of 28 insomniacs aged 55 and over. Participants were matched for severity of insomnia and then randomly assigned to stimulus control or imagery training. Each treatment consisted of six group sessions, and sleep was assessed by diaries and a sleep-activated clock. At the end of treatment and at one-year follow-up, although both treatments were shown to have had a significant impact upon insomnia, stimulus control demonstrated a greater effect size.

Despite this, no participants slept for an average of more than six hours per night either before or after intervention, which Morin and Azrin interpret as a possible ceiling
effect, at least for this age group. The efficacy of stimulus control techniques in this study has encouraging implications for clinicians, due to the relatively brief therapist commitment required for change. Unfortunately, Morin and Azrin excluded participants receiving psychiatric care so it cannot be concluded that equivalent results would be obtained with this population.

Cognitive

Fichten et al. (2001) present a cognitive-behavioural model of insomnia (Fig 1). They state that, during the night, negative cognitions are active in insomniacs. These cognitions include worries about sleep and the consequences of not getting enough sleep, negative self-statements and other anxious thoughts. This cognitive activity is linked to the other aspects of the model, namely distress, maladaptive behaviours and the perception that time is dragging. Fichten et al. predict that minimising negative
Figure 2: Cognitive model of the maintenance of insomnia (Harvey, 2002)
thoughts will be an effective treatment approach, as these either impact directly upon sleep or via any of the other components of the model. Unfortunately, the model does not make predictions regarding insomniacs' daytime cognitions or functioning. It also fails to delineate specific mechanisms via which the different components influence each other, which makes it difficult to test empirically.

Harvey (2002) devised a cognitive model of the maintenance of insomnia (Fig 2) which draws on cognitive theories for a range of psychological disorders and psychological theories of insomnia. The model's starting point is excessively negatively toned cognitive activity; similar to Fichten's model, this corresponds to thoughts about getting enough sleep and the impact of sleep deficit. She proposes that these cognitions cause insomniacs to become aroused and distressed, which leads them to increase their attention to perceived threats to sleep, for example the awareness that they do not feel tired. The detection of such stimuli then heightens the initial worry that caused arousal and distress, establishing a vicious cycle. Harvey suggests that these processes give rise to distorted perceptions of deficit, that is, sufferers under-estimate the duration of their sleep and over-estimate the impact of insomnia on their daytime functioning. This distortion increases negative cognitive activity, setting up another vicious cycle.

Harvey also identifies two additional influences on negative cognitive activity: dysfunctional beliefs about sleep, and counter-productive safety behaviours. Relevant beliefs might include: 'I must have eight hours sleep per night to adequately perform my daytime activities' or 'Insomnia is bad for my physical or mental well-being', and serve to heighten negative cognitive activity. Common safety behaviours include staying in bed when unable to sleep, and trying not to think about sleep. Harvey argues that safety behaviours serve a paradoxical function because, although they are designed to counteract negative cognitive activity, they actually increase both cognitive activity and the extent to which dysfunctional beliefs about sleep are held to be true, by preventing their disconfirmation.

Harvey's model of the maintenance of insomnia addresses the limitations described in relation to Fichten et al.'s model, i.e. it makes specific and testable predictions, which
enable us to incorporate existing evidence in order to consider its credibility. Harvey also considers daytime functioning, an area which has been absent from the majority of research conducted in this field. For example, she predicts that insomniacs will underestimate the amount and quality of obtained sleep, and selectively attend to and distort perceptions of daytime drowsiness and dysfunction. Another strength of the model is its emphasis on treatment recommendations; Harvey suggests addressing selective attention and monitoring, distorted perceptions of deficit, dysfunctional beliefs, and safety behaviours. The fact that the model has so recently been proposed means that it has not been subject to extensive testing. Although Blake (2002) investigated its applicability to insomnia among adults with anxiety disorders, it has not been examined with older adults: the present study will test the model with an older clinical population. A review of current available evidence is presented below.

Evidence relating to Harvey’s model of insomnia

The following review of available evidence will focus around several key points. Firstly, in order to critique Harvey’s cognitive model of insomnia, it will be important to establish the presence of each variable described in the model. It will then be important to consider evidence regarding the predicted relationships between different variables. Lastly, given the increased incidence of insomnia observed among older adults, and adults with mental health problems, it is especially important to determine whether the available evidence applies to these groups.

Arousal and distress

The link between arousal and insomnia is well established. Nicassio, Mendlowitz, Fussell and Petras (1985) developed a measure of pre-sleep arousal (the Pre-Sleep Arousal Scale) and, in line with previous research, concluded that cognitive arousal was more closely related to sleep-onset difficulty than physiological arousal. This finding would appear to provide some support for cognitive models of insomnia, and
was replicated by Fichten et al. (2001) in their sample of 605 insomniacs aged 50 and above.

As noted previously, distress is a necessary feature for the diagnosis of clinical insomnia. Its relevance to a cognitive-behavioural model is implied in a study conducted by Morin, Kowatch, Barry and Walton (1993). Twenty-four adults aged 60 and above were randomly assigned to a waiting list control group or to cognitive-behavioural treatment. Treatment involved education regarding age-related changes in sleep and sleep hygiene techniques, behavioural techniques to improve sleep hygiene, and cognitive restructuring of dysfunctional thoughts about sleep. Due to its success, those initially assigned to the waiting list were subsequently offered this treatment. Sleep was assessed by both PSG and daily sleep diaries, and improved significantly among those who received cognitive-behavioural treatment, both on completion of treatment and at a one-year follow-up. Rating scales recorded significant reductions in distress, even when improvements in sleep were modest. This is consistent with Harvey's predictions. The presence of modest improvements in sleep might reflect the ceiling effect suggested by Morin and Azrin (1988).

Morin et al.'s (1993) sampled age range (adults aged 60 and above) does not match service organisation in the UK, whereby a distinction is typically made between adults and older adults at age 65. None of the studies reviewed in this section have included participants diagnosed with secondary insomnia and/or comorbid psychopathology. Nonetheless, their findings support Harvey's model by demonstrating relationships between poor sleep and arousal and distress.

**Negatively toned cognitive activity**

Many researchers have studied the pre-sleep cognitions of insomniacs. Watts, Coyle and East (1994) examined the association between insomnia and worry with a sample of 79 adults. They found that insomniacs demonstrated significantly increased

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2 This study is discussed in more depth in relation to negatively toned cognitive activity (p.181).
frequency of thoughts relating to sleep as compared to “non-insomniac worriers” and controls. Although not rated in terms of negative or positive thoughts, the fact that these thoughts focused on wanting to sleep, noise and other distractions, being unable to sleep and worries about being tired the next day suggests that they were negatively toned, as would be predicted by Harvey’s model.

Fichten et al. (2001) administered numerous questionnaires to a sample of 605 insomniacs aged 55 and above to examine relationships between sleep, distress, cognitions and psychological adjustment. Although not predicted, positive thoughts were found to be more common during the pre-sleep period than negative or worry cognitions. These were followed in frequency by worried thoughts regarding friends and family. Even though positive thoughts were the most common pre-sleep cognitions, significant relationships were found between poor psychological adjustment, poor sleep and negative thinking, which is consistent with Harvey’s model. As with much research in this area, the reported relationships are correlational, so no causality can be assumed. Again, the age range sampled does not reflect the cut-off at age 65 by which service provision is organised in the UK.

Similar results were found by Fichten et al. (1998), who found no difference between the frequency of positive thoughts among good sleepers, and poor sleepers with and without distress. They suggest that participants used positive thoughts to counteract negative thoughts and reduce sleep-onset latency. As participants were not receiving treatment for insomnia, this can be assumed to be a naturally occurring, therapeutically naïve, coping mechanism. By contrast, and in accordance with Harvey’s predictions, significant correlations were obtained between negative thoughts and sleep variables, as measured by self-report questionnaires.

Finally, Wicklow and Espie (2000) recruited a non-clinical sample of 21 insomniacs with an average age of 36. They found that twenty per cent of pre-sleep cognitions related to sleep and the consequences of poor sleep. Rehearsal, planning and problem-solving were the most commonly reported strategies used to manage these cognitions.
The studies reviewed here have each demonstrated negatively toned cognitive activity among insomniacs. Worries about getting to sleep and the consequences of insomnia would appear to be common, and might be addressed via rehearsal, planning, problem-solving. At this stage, the role of positive thoughts remains uncertain. Again, none of these studies included participants with comorbid psychological disturbance, or focused exclusively on the over-65 age group.

Selective attention and monitoring

By contrast with negative cognitive activity, the selective attention and monitoring component of Harvey’s model has received far less attention. In a parsimonious study, Harvey and Schmidt (2001) explored this area with 30 good sleepers and 30 insomniacs. Participants in each group were randomly assigned to two conditions, one of which required them to monitor the clock during the pre-sleep period. Across the two groups of participants, those instructed to ‘clock-watch’ demonstrated a significantly longer sleep onset latency and increased worry about falling asleep, independently of their status as insomniacs or good sleepers. This clearly demonstrates the unhelpful role of this behaviour during the pre-sleep period, but more research is needed to provide further support for this aspect of the model and particularly with older adults, and those with mental health difficulties.

Distorted perception of deficit

Suggestions that insomniacs over-estimate sleep-onset latency are widespread in the research literature. In a rare study which quantifies this phenomenon, Wicklow and Espie (2000) report that the sleep diaries kept by their sample of 21 adult insomniacs overestimated sleep-onset latency by an average of 100 per cent. Despite this however, they still observed a modest but highly significant correlation between sleep data recorded by diaries and actigraphes ($r = 0.42, p < .001$).

Van Egeren, Haynes, Franzen and Hamilton (1983) studied subjective sleep quality and other variables in 34 adult insomniacs, who were required to sleep in a laboratory for
five nights. Participants' estimates of sleep quality became less accurate as their awareness of environmental stimuli increased. This is consistent with Harvey's model, suggesting a relationship between selective attention and monitoring of the environment, and distorted perceptions of deficit. Also consistent with Harvey's model was Van Egeren et al.'s finding that negative cognitions regarding physical sensations, environmental cues and sleep were associated with increased sleep-onset latency and increased concern about sleep. Again, it will be important to replicate these studies with older adults, and adults with mental health difficulties, as insomnia is more prevalent among these groups.

Dysfunctional beliefs

Morin, Stone, Trinkle, Mercer and Remsberg (1993) studied the sleep-related beliefs, attributions and expectations of 145 adults aged 55 and over, half of whom were due to attend a sleep disorders clinic for assistance with insomnia. As with the other studies reviewed here, participants with comorbid mental health difficulties were excluded from the study. Participants who had been referred to the sleep clinic could be differentiated from control participants on the basis of their beliefs about sleep. The most important beliefs in making this distinction appeared to be those which concerned the potential consequences of insomnia, for example, the belief that it could lead to physical or mental ill-health, or impaired daytime functioning, and beliefs expressing hopelessness or helplessness regarding sleep. However, results were mixed across participants, necessitating a qualitative analysis of individuals' data to determine which beliefs were endorsed and to what extent. Morin et al. recommend further research to identify the positive or negative influence of particular beliefs, and the impact of differing levels of endorsement. As with negative cognitive activity, they note that their data are cross-sectional and advocate research to identify whether dysfunctional beliefs are causative in insomnia, or vice versa. Again, it would be helpful to replicate this work with an older adult population with mental health difficulties.
Safety behaviours

Harvey (2002) suggests that thought and imagery control are common safety behaviours in individuals' attempts to control insomnia. The counter-productive nature of such safety behaviours has been demonstrated in relation to a range of psychological disorders, including post-traumatic stress disorder (Ehlers & Clark, 1999), social phobia (Wells et al., 1995) and obsessive-compulsive disorder (Salkovskis, 1999).

Harvey (2001) adapted the Thought Control Questionnaire (Wells and Davies, 1994) for use with an insomniac sample. She administered the revised questionnaire to 60 young adults, 30 of whom were insomniacs. Results demonstrated that insomniacs engaged in more frequent thought suppression than good sleepers. Good sleepers were more likely to use social control and replacement, and insomniacs reported increased worry and thought reappraisal. Harvey suggests utilising the techniques used by good sleepers in the treatment of insomnia. She also identifies a need for further research regarding the role of thought reappraisal, as she suggests that its use might be more adaptive when used during the daytime than during the pre-sleep period, when it appears to have the potential to lengthen sleep-onset latency and reduce sleep quality. Again, these results require replication in both clinical and older adult populations.

Summary

The research reviewed here has been generally consistent with Harvey's (2002) cognitive model of insomnia. Several studies have demonstrated that both adult and older adult insomniac populations engage in negative cognitive activity. In addition, Fichten et al. (2001) identified a relationship between such activity and poor sleep in older adults. Similarly, Nicassio et al. (1985) reported the presence of arousal and related its presence to delayed sleep-onset in adults. Distress was studied by Morin, Kowatch, Barry and Walton (1993) who both noted its presence and its amenability to cognitive-behavioural treatment, with adults aged 60 and over. With an adult sample, Harvey and Schmidt (2001) demonstrated a relationship between clock-watching - as an example of selective attention and monitoring - sleep-onset latency and negative
cognitive activity. Distorted perceptions of deficit have been recorded in adults by Wicklow and Espie (2000), and related to selective attention, in the form of external stimuli, by Van Egeren et al. (1983).

The presence of dysfunctional beliefs in older adults and safety behaviours in adult insomniacs has been established empirically (Morin, Stone, Trinkle, Mercer & Remsberg, 1993; Harvey, 2001), but their relationship to each other, and to negative cognitive activity remains uncertain.

Questions for further research

The research reviewed here has included predominantly adult samples. Due to the increased incidence of insomnia among older adults, it is especially important to ensure that the models proposed to explain insomnia, and treatment recommendations derived from them, are relevant to this age group, a point acknowledged by Harvey (2002). Because the lifestyles of older adults and the physiology of their sleep differ from those of younger people, it cannot be assumed that Harvey's model will apply to this population. Amongst those studies that have used older adult samples, differing age ranges have been adopted, including minimum ages of 55 and 60 years. As service provision in the UK tends to be organised around a cut-off age of 65 years, this would seem to represent a meaningful criterion from which to sample research participants, especially as it also the current UK retirement age, which corresponds to the social factors mentioned earlier and minimises the risk of results being confounded by participants' employment status.

Participants with comorbid psychopathology have been excluded from the majority of research studies. The elevated rate of insomnia among adults with mental health problems again dictates that attempts must be made to understand and explain their difficulties in order that effective treatment(s) can be offered. As with older adults, there may be a range of additional factors which impact upon the insomnia experience of this group. Lastly, research studies have tended to exclude participants with subthreshold insomnia, which does not meet DSM criteria for diagnosis; if insomnia is
seen as representing one end of a continuum rather than a distinct category, it will be useful to include participants whose sleep experiences fall across this range.

Although the research presented appears to be consistent with Harvey’s model, there remain areas that require further consideration. For example, no studies appear to have examined the relationships between dysfunctional beliefs about sleep, safety behaviours including thought control strategies, negative cognitive activity and insomnia. In addition, it will be valuable to further examine Morin et al.’s (1993) suggestion that it is important to consider the individual beliefs about sleep endorsed by individual participants, and the extent of their endorsement.

Objectives of current research

This research study will test part of Harvey’s (2002) model with a population of older adults and address some of the issues discussed above. The incidence and extent of insomnia and mental health difficulties will be identified among a clinical sample of participants aged 65 and over who have mental health difficulties. In order that subthreshold cases of insomnia can be included, and to address difficulties regarding diagnosis, sleep quality and mental health status will be treated as ordinal, rather than categorical, data. The high estimates of comorbidity between insomnia and mental health difficulties identified by previous research suggests that there might be a relationship between the severity of insomnia and severity of mental health difficulty. Relationships between aspects of Harvey’s model which have not yet been demonstrated empirically - dysfunctional beliefs, safety behaviours such as thought control strategies and negative cognitive activity - will be investigated. The relationships between individual beliefs about sleep and insomnia and negative cognitive activity will also be explored. Harvey’s suggestion that these areas of the model represent important areas for treatment provides further rationale for their importance in this research.
Hypotheses

1. Previous research has reported an increased prevalence of insomnia among older adults, and among adults with mental health difficulties. It is therefore expected that older adults with mental health difficulties will demonstrate a significant incidence of insomnia, as compared to previous research.

2. The reported comorbidity data regarding the increased prevalence of insomnia among adults with mental health difficulties suggests that the severity of sleep disturbance will increase as the severity of psychological disturbance increases.

3. Harvey’s model predicts that adults who suffer with insomnia will demonstrate increased negative cognitive activity, increased dysfunctional beliefs about sleep and increased use of counter-productive safety behaviours, such as thought control strategies. It is predicted that this pattern will also be observed among older adults with mental health difficulties who suffer with insomnia.

4. Previous research and Harvey’s model predict that negative cognitive activity is a stronger predictor of insomnia than physical tension. It is predicted that there will be a stronger relationship between insomnia and negative cognitive activity than between insomnia and physical tension in older adults with mental health difficulties who suffer with insomnia.

5. Harvey’s model predicts that the safety behaviours, including thought control strategies, employed by adult insomniacs influence their dysfunctional beliefs about sleep, i.e. increased use of counter-productive thought control strategies will be associated with increased dysfunctional beliefs about sleep. It is predicted that there will also be a relationship between safety behaviours and dysfunctional beliefs about sleep in older adults with mental health difficulties who suffer with insomnia.

6. Harvey’s model predicts that negative cognitive activity among adult insomniacs is influenced by the extent of their dysfunctional beliefs about sleep, i.e. increased
negative cognitive activity will be observed among those with increased dysfunctional beliefs about sleep. It is expected that there will also be a relationship between negative cognitive activity and dysfunctional beliefs about sleep in older adults with mental health difficulties who suffer with insomnia.

7. Finally, Harvey's model predicts that adult insomniacs will demonstrate a relationship between negative cognitive activity and the use of safety behaviours, including thought control strategies, i.e. negative cognitive activity will be associated with increased use of thought control strategies. It is predicted that this relationship will also be observed in older adults with mental health difficulties who suffer with insomnia.
Method

Participants

48 participants were recruited from two Community Mental Health Teams (CMHTs) for older adults (age 65 and over). Clinicians’ knowledge or judgements were used to identify service users who were likely to be suffering from dementia and those whose fluency in the English language was thought to compromise their capacity to give informed consent. These service users were then excluded from the study. All service users who met the criteria for inclusion in the study were informed about the study by clinicians working with them, and provided with sufficient information to enable them to opt into the project (see Appendix E for Participant Information and Consent Form).

Demographic data were collected and are recorded within the results section.

Measures

Demographic information was collected to enable consideration of the sample’s representativeness. This followed the guidelines recommended by the NHS Trust Ethics Committee (see Appendix F, Part 1).

Measure of mental health status

The 12-item General Health Questionnaire (GHQ-12, Goldberg, 1992) was used to measure mental health status (see Appendix F, Part 2, Section A). This is an abbreviated version of the 60-item GHQ, with equivalent validity and reliability (Johnston, Weight & Weinman, 1995; Mathers, Shipton & Shapiro, 1993). It is a 12-item self-report measure which assesses psychiatric disorder among community samples. Johnston et al. (1995) report internal consistency of between 0.82 and 0.90 using Cronbach’s alpha, split-half reliability of 0.83 and test-retest reliability of 0.73. They state that its sensitivity in detecting psychiatric disorder has been found to be
93.5% and its specificity in detecting disorder 78.5%. The GHQ-12 has been widely used internationally for both clinical and research purposes with older adults; research studies have found it capable of differentiating clinical from control subjects (Papassotriopoulos & Reinhard; 1998 & 1999). Johnston et al. describe two scoring systems; the first has a range from 0 to 12, where a score greater than or equal to 8 represents a 'cut-off' point in identifying clinically significant levels of distress. Alternatively, Likert scoring, with a range from 0 to 36 provides greater information regarding the severity of disorder and less skewed results (Johnston et al., 1995). This study will look at the results obtained from both scoring systems.

Measure of insomnia

The Pittsburgh Sleep Quality Index (PSQI; Buysse, Reynolds, Monk, Berman and Kupfer, 1989) is a 19-item self-report questionnaire which was used to measure the sleep deficit component of Harvey's model (see Appendix F, Part 2, Section B). The PSQI measures 7 aspects of sleep disturbance: subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleeping medications and daytime dysfunction, and provides a global score. Initial data obtained from insomniacs, good sleepers, control participants and depressed patients, with mean ages between 40 and 60 years, demonstrated internal consistency, stability over time, and accurate discrimination of patients from controls (Buysse et al., 1989). Although initial validation data were conducted with adults, this measure has also been widely used with older adults, (e.g. Lai, 2002; Krakow et al.; 2001) using the established cut-off point of a global score equal to or greater than five to define insomnia.

Measures of negative cognitive activity, physical tension and dysfunctional beliefs about sleep

Espie, Brooks and Lindsay (1989) devised the Sleep Disturbance Questionnaire (SDQ), a 12-item self-report questionnaire which uses a 5-point Likert scale to determine the relative importance of physiological, behavioural and cognitive factors in individuals' insomniac experiences. Its 'Mental Anxiety' subscale is composed of 6
questions and was used to measure negative cognitive activity. The 3-item ‘physical tension’ subscale was used to compare the influences of negative cognitive activity and physical tension at night (see Appendix F, Part 2, Section C). The SDQ has been used in previous research to measure negative cognitive activity in the pre-sleep period (e.g. Blake, 2002). Analysis of questionnaires completed by 42 individuals suffering from “chronic insomnia” (average age 46.8 years) via principal components analysis yielded results consistent with the hypothesised three factors (Espie et al., 1989).

Morin, Stone, Trinkle, Mercer and Remsberg (1992) published the Dysfunctional Beliefs and Attitudes about Sleep (DBAS), a 28-item self-report questionnaire designed to identify cognitions about sleep during assessment and after treatment. It focuses on five areas of cognitive activity: misconceptions regarding the cause of insomnia; misattributions or amplifications regarding its consequences; unrealistic expectations about sleep; beliefs regarding the control and predictability of sleep; and, inaccurate beliefs about sleep-promoting behaviours. The DBAS-10, described below, was used to assess participants’ beliefs about sleep (see Appendix F, Part 2, Section E).

Espie et al. (2000) administered the DBAS and SDQ to 178 adults and assessed the psychometric properties of the scales. Their analyses enabled the development of the 10-item DBAS (DBAS-10), which demonstrated superior statistical properties to the original 28-item DBAS. Espie et al. (2000, p.146) conclude that both measures have “a credible scientific basis” and are useful tools for both describing populations and measuring change. Espie et al. excluded participants with comorbid mental health problems, noted to include depression and post-traumatic stress disorder. In addition, they do not report their sample’s age range, stating only that their mean age was 50 years; it is therefore not possible to ascertain whether participants aged over 65 were included. However, the scale has successfully been used to assess outcome of cognitive-behavioural therapy among 75 adults aged from 40 to 80 years (Edinger, Wohlgemuth, Radtke, Marsk and Quillian, 2001).
Measure of thought control strategies as safety behaviours

Harvey (2001) modified Wells and Davies' (1994) Thought Control Questionnaire to create the 43-item Thought Control Questionnaire-Insomnia (see Appendix F, Part 2, Section D). The TCQ-I assesses the use of thought control strategies as counter-productive safety behaviours related to insomnia. The original TCQ has been well validated and assesses the use of five thought control strategies: distraction, punishment, reappraisal, social control and worry (Harvey, 2001). Harvey added items relating to getting to sleep, and subdivided the distraction component into suppression and replacement, in line with more recent cognitive evidence. The modified questionnaire’s reliability and validity are currently being investigated (Harvey, 2003, personal correspondence).

Procedure and data analysis

An initial pilot study ensured that questionnaires could be understood by adults aged over 65 and determined the time necessary for their completion (approximately 30 minutes). This was conducted via personal correspondence with adults known to the researcher (age range 74-84 years), and did not include older adults with mental health difficulties. No difficulties with completing the questionnaire were reported.

Service users attending either of the two older adult CMHTs were told about the study by clinicians working with them. Those who appeared interested were given an information sheet, consent form, questionnaire (Appendices E and F) and Freepost envelope, and could opt in to the study if they wished. The consent form asked participants to whether they wanted to complete questionnaires by post or over the telephone. Those wishing to complete the questionnaire by mail already had all the required paperwork so could proceed with the research. Those wishing to complete the questionnaire by telephone could return their consent form giving a contact number and preferred time for the researcher to call. No participants chose to take part in this
way. All consent forms and questionnaires were returned to the researcher in Freepost envelopes either via mail or via clinicians working with participants.

Completed consent forms and questionnaires were allocated a number, enabling each participant’s data to be recalled and omitted from the study if requested at a later date. They were then stored separately in locked offices. All questionnaires were scored in agreement with the authors’ instructions and a database developed for data analysis using the Statistical Package for the Social Sciences -version 10.1 (SPSS 10.1).

**Power analysis**

A priori power analysis was conducted using G-POWER (Faul & Erdfelder, 1992). This was based upon the intention to analyse data using multiple regression with four predictor variables to achieve a medium effect size. The criteria for power was set at 0.80 and alpha was set at 0.05. This recommended that a minimum of 85 participants be recruited. As this was not met, a post-hoc power analysis was conducted, which demonstrated that the obtained sample, of 48 participants, enabled correlation analyses to be conducted with power of 0.7, with alpha again set at 0.05.

**Ethical approval**

The research was reviewed and approved by Eastern Surrey Local Research Ethics Committee, the University of Surrey Research Ethics Committee and Surrey Oaklands NHS Trust Research and Development (R&D) Committee (Appendices B, C and D).

**Data analysis**

The statistical package SPSS - version 10.1 was used to analyse the data. Pearson’s product moment correlations were planned to investigate relationships between results obtained via the GHQ-12, PSQI, SDQ, TCQ-I and DBAS-10. Being a parametric analysis, this assumes that data are normally distributed. As several variables did not meet this criterion - the Worry and Punishment subscales of the TCQ-I, and items 1, 5,
6 and 8 of the DBAS-10 - attempts were made to transform the data. As these were unsuccessful, they were subject to non-parametric analysis, using Spearman’s rank order (rho) correlations.
Results

Demographic data

48 participants took part in the study. 179 questionnaires were given out, which corresponds to a 27% response rate. 40 (83.3%) participants were female, and 8 (16.7%) were male. 43 (89.6%) participants stated that their country of origin was England, 3 (6.3%) stated Wales, and 2 (4.2%) stated ‘Other’. All participants (100%) described their ethnic origin as ‘White’. 47 (97.9%) participants gave their age. The reported range was 65 to 86 years. Participants’ mean age was 74.66 years and the standard deviation was 5.51.

Data collected by the Health Records department of the NHS Trust demonstrate that, during the period of data collection, 1610 service users were open to the Older Adult CMHTs. 11.12% (179 service users) of this sample were therefore invited to participate in the study. However, the data available from Health Records do not record how many of the overall sample were seen by a professional working in either CMHT during the period of data collection, were suffering from dementia or had insufficient fluency in the English language to give informed consent, and were therefore excluded from participation in this study.

However, the available data do reflect the uneven gender distribution observed among participants. 1126 (69.94%) service users were female, and 483 (30.00%) were male (1 service user’s gender (0.06%) was unrecorded. The data also demonstrate a mean age of 79.76 (range 65-104), which is significantly greater than that of the participants (t = -6.35, df = 46, p < .001).

The majority of service users open to the CMHTs (852, 52.92%) during the period of data collection had had their first appointment during the previous nine months. 523 (32.48%) had had first appointments in 2002, 197 (12.24%) in 2001, and 36 (2.24%) between 1997 and 2000. Data regarding marital status were not available for the majority of service users (656, 40.75%); 490 (30.43%) were married or living with
partners, 398 (24.72%) were widowed, divorced or separated, and 66 (4.10%) were single.

Data screening

Variables were screened using the Kolmogorov-Smirnov test to determine whether they were normally distributed. When data did not meet this criterion, as in the case of TCQ-I Worry and Punishment subscales, and responses to questions 1, 5, 6 and 8 of the DBAS-10, attempts were made to transform them. As this was not successful with any of these variables, they were subject to non-parametric analysis. All data were analysed using the statistical package SPSS - version 10.1.

Internal consistency of measures

Cronbach’s alpha coefficients were calculated to indicate the internal consistency of the measures used with the current sample. Results were as follows: GHQ-12 = .94, PSQI = .74, SDQ = .94, TCQ-I = .91 and DBAS-10 = .83 and therefore indicate good internal consistency.

Descriptive statistics

Mental health status

All participants completed the GHQ-12. Using the traditional GHQ-12 scoring system, a range was obtained from 0 to 12, with a mean of 5.50 and a standard deviation of 4.34. 19 (39.56%) participants reported scores equal to or greater than 8; this represents the accepted cut-off point in identifying clinically significant levels of distress (Johnston et al., 1995). The Likert scoring system obtained a mean of 17.85 and standard deviation of 8.25, with a range of 4 to 34. This score is significantly greater than the mean of 12.3 obtained using the Likert scoring system by Lewis and Araya (1995) in a sample of adults attending a primary care clinic in the same geographical area in which this study was conducted (t = 4.666, df = 47, p < .001),
suggesting an enhanced level of distress amongst this population. However, it can be compared to data collected pre- and post- short-term counselling by Mathers et al. (1993), with a pre-counselling mean of 23.1 and a post-counselling mean of 13.8, and would appear to be consistent with scores during treatment.

Sleep quality

Scores obtained on the PSQI are reported below. Each of the index scores demonstrated a range from 0 to 3, thereby covering the scale in its entirety. Some participants did not complete all parts of the questionnaire, and have therefore been excluded from the affected areas of the analysis.

Table 1: Mean PSQI subscale scores

<table>
<thead>
<tr>
<th>Index</th>
<th>Number of participants included in analysis</th>
<th>Mean score</th>
<th>Standard deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subjective sleep quality</td>
<td>47</td>
<td>1.21</td>
<td>.81</td>
</tr>
<tr>
<td>Sleep latency</td>
<td>44</td>
<td>1.36</td>
<td>1.12</td>
</tr>
<tr>
<td>Sleep duration</td>
<td>45</td>
<td>1.00</td>
<td>.95</td>
</tr>
<tr>
<td>Habitual sleep efficiency</td>
<td>44</td>
<td>1.23</td>
<td>1.12</td>
</tr>
<tr>
<td>Sleep disturbances</td>
<td>48</td>
<td>1.65</td>
<td>.67</td>
</tr>
<tr>
<td>Use of sleeping medication</td>
<td>47</td>
<td>0.89</td>
<td>1.24</td>
</tr>
<tr>
<td>Daytime dysfunction</td>
<td>46</td>
<td>1.33</td>
<td>.82</td>
</tr>
<tr>
<td>Global score</td>
<td>43</td>
<td>8.67</td>
<td>4.72</td>
</tr>
</tbody>
</table>

Global scores ranged from 0 to 19 (the highest possible score was 21). The obtained mean score of 8.67 is above the clinical cut-off point of 5 (Buysse et al., 1989). Indeed, 34 (79.1%) of the 43 participants whose global scores could be calculated scored at or above this cut-off, denoting clinically significant poor sleep.
The highest mean PSQI subscale score, of 1.65, corresponded to sleep disturbances, and can therefore be seen to represent the most frequent area of difficulty for this sample. Examples of sleep disturbances recorded included needing to get up to use the toilet, worrying about one’s health and family members, looking after a partner and external noise. Sleep latency and daytime dysfunction yielded the next highest mean scores, of 1.36 and 1.33 respectively, suggesting that participants were likely to have some difficulty getting to sleep and coping with daytime tiredness. The mean scores for subjective sleep quality and sleep duration of 1.21 and 1.00 represent less significant sources of difficulty.

The obtained mean score for the ‘use of sleeping medication’ index was low (0.89). The majority of participants (28, 58.3%) stated that they had not used over the counter or prescription medication to aid sleep in the last month. However, amongst those who reported using medication to aid sleep, there appeared to be a tendency for frequent usage: 6 (12.5%) participants reported using it less than once per week, 3 (6.3%) reported using it once or twice per week and 10 (20.8%) reported using it three or more times per week.

**Negative cognitive activity**

SDQ data are presented below. 3 participants did not answer all questions, so are excluded from analysis.

The ‘Mental Anxiety’ subscale demonstrated a mean score of 16.60 (standard deviation 6.45). The obtained range of 6 to 30 covered all possible scores. This is lower than the means recorded with adult insomniacs with and without comorbid anxiety disorders in Blake’s (2002) study, of 23.6 and 22.5 respectively.

The ‘Physical Tension’ subscale demonstrated a mean score of 7.87 (standard deviation 2.87). The obtained range of 3 to 15 included all possible scores. Like the Mental Anxiety subscale score, the Physical Tension subscale mean score is also lower...
than those reported by Blake, with 11.7 for the insomniacs with anxiety disorders and 9.8 without.

The ‘sleep pattern problem’ subscale demonstrated a mean score of 6.31 (standard deviation 2.76). The obtained range was 3 to 13, of a possible 3 to 15. The obtained SDQ total score was 30.78 (standard deviation 10.776). Observed scores ranged from 12 to 58, of a possible 12 to 60. The sleep pattern problem subscale was not used in further analysis as it was not the subject of any hypotheses. Similarly, the SDQ total score was also not used in analyses, as the two variables of interest - Mental Anxiety and Physical Tension - were explored as individual variables rather than as components of a composite score.

Thought control strategies (safety behaviours)

TCQ-I subscale scores are presented below:

Table 2: Mean TCQ-I subscale scores

<table>
<thead>
<tr>
<th>Index</th>
<th>Number of participants included in analysis</th>
<th>Mean</th>
<th>Standard deviation</th>
<th>Observed range</th>
<th>Available range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suppression</td>
<td>39</td>
<td>10.44</td>
<td>2.46</td>
<td>5-15</td>
<td>5-20</td>
</tr>
<tr>
<td>Replacement</td>
<td>38</td>
<td>18.18</td>
<td>4.59</td>
<td>10-27</td>
<td>9-36</td>
</tr>
<tr>
<td>Punishment</td>
<td>39</td>
<td>8.77</td>
<td>2.97</td>
<td>6-21</td>
<td>6-24</td>
</tr>
<tr>
<td>Reappraisal</td>
<td>38</td>
<td>17.11</td>
<td>4.90</td>
<td>9-29</td>
<td>9-36</td>
</tr>
<tr>
<td>Social control</td>
<td>39</td>
<td>14.90</td>
<td>4.06</td>
<td>7-26</td>
<td>7-28</td>
</tr>
<tr>
<td>Worry</td>
<td>39</td>
<td>12.72</td>
<td>4.33</td>
<td>7-25</td>
<td>7-28</td>
</tr>
<tr>
<td>Total Score</td>
<td>38</td>
<td>82.34</td>
<td>16.00</td>
<td>53-129</td>
<td>43-172</td>
</tr>
</tbody>
</table>
Figure 3: Mean TCQ-I subscale scores represented as a percentage of its maximum possible score

As the TCQ-I subscales have different maximum scores, Figure 3 shows the mean score for each subscale represented as a percentage of the maximum possible score for that subscale. This demonstrates that social control was the most frequently endorsed and punishment was the least commonly endorsed strategy.

Dysfunctional beliefs about sleep

Results obtained from the DBAS-10 are presented below. The obtained range was 0 to 100 for questions 3, 6, 7, 8 and 9. The obtained range for question 1 was 1 to 100, 3 to 100 for question 2, 2 to 100 for question 4, 0 to 92 for question 5 and 0 to 98 for question 10.
Table 3: DBAS-10 results

<table>
<thead>
<tr>
<th>Belief</th>
<th>Number of respondents</th>
<th>Mean score</th>
<th>Standard deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I need 8 hours of sleep to feel refreshed and function well during the day.</td>
<td>47</td>
<td>62.74</td>
<td>32.75</td>
</tr>
<tr>
<td>2. When I don’t get a proper amount of sleep on a given night, I need to catch up on the next day by napping or on the next night by sleeping longer.</td>
<td>48</td>
<td>61.02</td>
<td>28.99</td>
</tr>
<tr>
<td>3. I am concerned that chronic insomnia may have serious consequences for my physical health.</td>
<td>47</td>
<td>40.36</td>
<td>32.92</td>
</tr>
<tr>
<td>4. When I have trouble getting to sleep, I should stay in bed and try harder.</td>
<td>47</td>
<td>45.64</td>
<td>31.26</td>
</tr>
<tr>
<td>5. I am worried that I may lose control over my abilities to sleep.</td>
<td>47</td>
<td>36.34</td>
<td>30.33</td>
</tr>
<tr>
<td>6. After a poor night’s sleep, I know that it will interfere with my daily activities on the next day</td>
<td>47</td>
<td>55.40</td>
<td>30.50</td>
</tr>
<tr>
<td>7. When I feel irritable, depressed or anxious during the day, it is mostly because I did not sleep well the night before.</td>
<td>44</td>
<td>51.20</td>
<td>31.21</td>
</tr>
<tr>
<td>8. When I sleep poorly on one night, I know it will disturb my sleep schedule for the whole week.</td>
<td>44</td>
<td>27.82</td>
<td>28.56</td>
</tr>
<tr>
<td>9. When I feel tired, have no energy, or just seem not to function well during the day, it is generally because I did not sleep well the night before.</td>
<td>46</td>
<td>51.15</td>
<td>30.36</td>
</tr>
<tr>
<td>10. I get overwhelmed by my thoughts at night and often feel I have no control over my racing mind.</td>
<td>45</td>
<td>56.31</td>
<td>30.93</td>
</tr>
<tr>
<td>Mean score</td>
<td>44</td>
<td>49.33</td>
<td>19.26</td>
</tr>
</tbody>
</table>
Figure 4: Mean scores of each belief (DBAS-10)

The following table demonstrates the number and percentages of participants endorsing each belief, as indicated by a score greater than 50, and ranked orders according to frequency of endorsement.
Table 4: Percentages of participants endorsing DBAS-10 beliefs and ranked orders

<table>
<thead>
<tr>
<th>Question</th>
<th>Number of respondents</th>
<th>Number of participants endorsing belief</th>
<th>Percentage of participants endorsing belief</th>
<th>Rank order</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>47</td>
<td>34</td>
<td>72.34</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td>48</td>
<td>31</td>
<td>64.58</td>
<td>3</td>
</tr>
<tr>
<td>3</td>
<td>47</td>
<td>18</td>
<td>38.30</td>
<td>8</td>
</tr>
<tr>
<td>4</td>
<td>47</td>
<td>20</td>
<td>42.55</td>
<td>7</td>
</tr>
<tr>
<td>5</td>
<td>47</td>
<td>17</td>
<td>36.17</td>
<td>9</td>
</tr>
<tr>
<td>6</td>
<td>47</td>
<td>26</td>
<td>55.32</td>
<td>5</td>
</tr>
<tr>
<td>7</td>
<td>44</td>
<td>26</td>
<td>59.09</td>
<td>4</td>
</tr>
<tr>
<td>8</td>
<td>44</td>
<td>8</td>
<td>18.18</td>
<td>10</td>
</tr>
<tr>
<td>9</td>
<td>46</td>
<td>24</td>
<td>52.17</td>
<td>6</td>
</tr>
<tr>
<td>10</td>
<td>45</td>
<td>30</td>
<td>66.67</td>
<td>2</td>
</tr>
</tbody>
</table>

Figure 5: Percentage of participants endorsing each DBAS-10 item
Table 4 and Figure 5 above demonstrate the numbers of participants endorsing each item on the DBAS-10. The most frequently endorsed belief was number 1, the belief that “I need 8 hours of sleep to feel refreshed and function well during the day”. The least frequently endorsed belief was number 8 “When I sleep poorly on one night, I know it will disturb my sleep schedule for the whole week”.

Statistical analysis

Variables that were normally distributed were analysed with Pearson’s product-moment correlations. As the data which did not meet the criterion of normal distribution (Worry and Punishment subscales of the TCQ-I, and items 1, 5, 6 and 8 of the DBAS-10) could not be transformed, they were analysed using Spearman’s Rank Order (rho) correlations.

Hypotheses 1 and 2: Older adults with mental health difficulties will demonstrate a significant incidence of insomnia. This will increase as the severity of mental health difficulties increases.

The PSQI total mean score of 8.67 is greater than the established cut-off point of 5 used to identify clinically significant scores (Buysse et al., 1989). 34 (79.07%) of the 43 participants for whom a PSQI total score could be calculated obtained a clinically significant score of 5 or more. This therefore denotes a significant incidence of insomnia and is consistent with the first hypothesis.

The obtained PSQI total mean score of 8.67 is lower than data obtained by Buysse et al. (1989) with both adult insomniacs recruited from a sleep clinic (mean 10.38, s.d. 4.57, mean age 44.8 years) and poor sleepers suffering from depression recruited from a psychiatric institution (mean 11.09, s.d. 4.31, mean age 50.9 years). Post-hoc tests demonstrated significant differences between the means obtained by these groups (t = -7.796, df = 47, p < .001 and t = -8.930, df = 47, p < .001, respectively), indicating a significantly lower PSQI total score in the current sample.
Pearson's product-moment correlation indicated that there was a significant positive correlation between the severity of mental health difficulty, as measured by the GHQ-12, and severity of insomnia, as measured by the PSQI total score \( (r = .576, p < .001) \). This hypothesis has therefore also been met.

There was no significant correlation between age and insomnia, as measured by the PSQI total score \( (r = -.086, p = .582) \). This demonstrates that, within this sample, insomnia did not worsen or improve with age.

**Hypothesis 3: Insomnia will be related to increased negative cognitive activity, dysfunctional beliefs and safety behaviours.**

The following table demonstrates the correlation co-efficients pertaining to negative cognitive activity, (as measured by the Mental Anxiety subscale of the SDQ) dysfunctional beliefs, (as measured by the DBAS-10) thought control strategies as safety behaviours (measured by the TCQ-I) and insomnia, as measured by the PSQI.

**Table 5: Correlations between negative cognitive activity, dysfunctional beliefs, safety behaviours and PSQI total scores.**

<table>
<thead>
<tr>
<th>Variables correlated with PSQI total score</th>
<th>Correlation coefficient</th>
<th>Significance level</th>
</tr>
</thead>
<tbody>
<tr>
<td>SDQ Mental Anxiety subscale</td>
<td>.707</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>TCQI Suppression subscale</td>
<td>.142</td>
<td>.402</td>
</tr>
<tr>
<td>TCQI Replacement subscale</td>
<td>.151</td>
<td>.372</td>
</tr>
<tr>
<td>TCQI Punishment subscale</td>
<td>.294</td>
<td>.077</td>
</tr>
<tr>
<td>TCQI Reappraisal subscale</td>
<td>.122</td>
<td>.471</td>
</tr>
<tr>
<td>TCQI Social control subscale</td>
<td>-.105</td>
<td>.536</td>
</tr>
<tr>
<td>TCQI Worry subscale</td>
<td>.453</td>
<td>.005</td>
</tr>
<tr>
<td>DBAS-10 total</td>
<td>.477</td>
<td>.002</td>
</tr>
</tbody>
</table>
This table demonstrates significant positive correlations between insomnia, as measured by the PSQI, and negative cognitive activity, as measured by the Mental Anxiety subscale of the SDQ, the Worry subscale of the TCQ-I, and dysfunctional beliefs, measured by the DBAS-10 (p < .01). The relationship between insomnia, as measured by the PSQI and the Punishment subscale of the TCQ-I approached significance (p = .077). These relationships are all in the predicted direction. Suppression, Replacement, Reappraisal and Social Control did not demonstrate significant relationships with insomnia, as measured by the PSQI.

The following table demonstrates the relationships between each item of the DBAS-10 and insomnia, as measured by the PSQI total score.

Table 6: Correlations between the PSQI and DBAS-10 item scores

<table>
<thead>
<tr>
<th>Variable correlated with the PSQI total score</th>
<th>Correlation coefficient</th>
<th>Significance level</th>
</tr>
</thead>
<tbody>
<tr>
<td>DBAS-10 item 1</td>
<td>-.381</td>
<td>.013</td>
</tr>
<tr>
<td>DBAS-10 item 2</td>
<td>-.090</td>
<td>.564</td>
</tr>
<tr>
<td>DBAS-10 item 3</td>
<td>.423</td>
<td>.005</td>
</tr>
<tr>
<td>DBAS-10 item 4</td>
<td>.039</td>
<td>.807</td>
</tr>
<tr>
<td>DBAS-10 item 5</td>
<td>.602</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>DBAS-10 item 6</td>
<td>.545</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>DBAS-10 item 7</td>
<td>.458</td>
<td>.003</td>
</tr>
<tr>
<td>DBAS-10 item 8</td>
<td>.320</td>
<td>.044</td>
</tr>
<tr>
<td>DBAS-10 item 9</td>
<td>.076</td>
<td>.636</td>
</tr>
<tr>
<td>DBAS-10 item 10</td>
<td>.457</td>
<td>.003</td>
</tr>
</tbody>
</table>

Two DBAS-10 items, questions 5 and 6, demonstrated highly significant relationships with insomnia, as measured by the PSQI total score (p < .001). These items describe beliefs regarding controllability of sleep and worry regarding daytime dysfunction. The
relationships between DBAS-10 items 1, 3, 7, 8 and 10 and insomnia were significant at $p < .05$. These beliefs describe needing 8 hours of sleep per night, daytime dysfunction, ongoing sleep disturbance and physical health consequences of insomnia and controllability. Non-significant relationships were found between items 2, 4 and 9 and insomnia ($p > .05$). These items addressed needing recovery nights, ‘trying harder’ to sleep and daytime consequences of poor sleep.

**Hypothesis 4:** Negative cognitive activity will be more closely related to insomnia than Physical Tension.

As stated above, the Mental Anxiety subscale of the SDQ was highly correlated with insomnia, as measured by the PSQI global score ($r = .707, p < .001$). Physical Tension also correlated highly with insomnia, again measured by the PSQI global score ($r = .685, p < .001$). As Physical Tension demonstrated a smaller correlation coefficient, Mental Anxiety can be seen to more closely related to insomnia.

**Hypothesis 5:** Safety behaviours will be related to dysfunctional beliefs about sleep

Table 7 (next page) demonstrates the strength of the relationship between dysfunctional beliefs about sleep, as measured by the DBAS-10 total score and each of the subscales of the PSQI.

This demonstrates that the relationship between dysfunctional beliefs and thought suppression is significant at the level of $p < .05$. The relationships between dysfunctional beliefs and punishment and worry are highly significant at $p < .001$. These relationships are in the predicted direction, i.e. increased insomnia is observed with increased use of suppression, punishment and worry. The relationships between dysfunctional beliefs and thought replacement, reappraisal and social control were not significant ($p > .05$).
Hypothesis 6: Negative cognitive activity will be related to dysfunctional beliefs about sleep.

The obtained correlation coefficient of $r = .631$ indicated a significant relationship at the $p < .001$ level between SDQ Mental Anxiety and DBAS-10 total scores. This indicates that increased negative cognitive activity was generally associated with increased dysfunctional beliefs.

Examination was then made of the relationships between individual DBAS-10 items and negative cognitive activity, as measured by the SDQ Mental Anxiety subscale. Results are presented in Table 8 (next page).

Four DBAS-10 items, questions 3, 5, 7 and 10, yielded highly significant relationships with negative cognitive activity, as measured by the SDQ Mental Anxiety subscale ($p < .001$). Questions 2, 6, 8 and 9 demonstrated significant relationships at the $p < .05$ level. Non-significant relationships were observed between items 1 and 4 and negative cognitive activity, as measured by the SDQ Mental Anxiety subscale ($p > .05$). These items referred to needing 8 hours of sleep per night and staying in bed when unable to sleep.
Table 8: Correlation coefficients regarding SDQ Mental Anxiety and DBAS-10 items

<table>
<thead>
<tr>
<th>Variable correlated with the SDQ Mental Anxiety subscale</th>
<th>Correlation coefficient</th>
<th>Significance level</th>
</tr>
</thead>
<tbody>
<tr>
<td>DBAS-10 item 1</td>
<td>-0.084</td>
<td>.584</td>
</tr>
<tr>
<td>DBAS-10 item 2</td>
<td>.388</td>
<td>.008</td>
</tr>
<tr>
<td>DBAS-10 item 3</td>
<td>.550</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>DBAS-10 item 4</td>
<td>.052</td>
<td>.734</td>
</tr>
<tr>
<td>DBAS-10 item 5</td>
<td>.509</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>DBAS-10 item 6</td>
<td>.414</td>
<td>.005</td>
</tr>
<tr>
<td>DBAS-10 item 7</td>
<td>.594</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>DBAS-10 item 8</td>
<td>.389</td>
<td>.010</td>
</tr>
<tr>
<td>DBAS-10 item 9</td>
<td>.368</td>
<td>.014</td>
</tr>
<tr>
<td>DBAS-10 item 10</td>
<td>.596</td>
<td>&lt; .001</td>
</tr>
</tbody>
</table>

Hypothesis 7: Negative cognitive activity will be related to safety behaviours.

Table 9 (next page) demonstrates the relationships between negative cognitive activity, measured by the Mental Anxiety subscale of the SDQ, and thought control strategies (safety behaviours), measured by the TCQ-I.

SDQ Mental Anxiety demonstrated its strongest relationship with Worry ($r = .539$, $p = .001$). Relationships between SDQ Mental Anxiety and Suppression, Replacement and Punishment were all significant at $p < .05$. These were in the predicted direction, i.e. increased negative cognitive activity was associated with increased use of worry, suppression, replacement and punishment. There was no significant relationship between SDQ Mental Anxiety and Reappraisal or Social Control ($p > .05$).
Table 9: Relationships between the SDQ Mental Anxiety subscale and TCQ-I

<table>
<thead>
<tr>
<th>Variables correlated with SDQ Mental Anxiety scores</th>
<th>Correlation coefficient</th>
<th>Significance level</th>
</tr>
</thead>
<tbody>
<tr>
<td>TCQI Suppression subscale</td>
<td>.327</td>
<td>.042</td>
</tr>
<tr>
<td>TCQI Replacement subscale</td>
<td>.421</td>
<td>.008</td>
</tr>
<tr>
<td>TCQI Punishment subscale</td>
<td>.474</td>
<td>.002</td>
</tr>
<tr>
<td>TCQI Reappraisal subscale</td>
<td>.112</td>
<td>.505</td>
</tr>
<tr>
<td>TCQI Social control subscale</td>
<td>-.143</td>
<td>.386</td>
</tr>
<tr>
<td>TCQI Worry subscale</td>
<td>.502</td>
<td>.001</td>
</tr>
</tbody>
</table>

Qualitative information

The GHQ-12 was the only questionnaire to which all participants answered every question. Each of the other questionnaires demonstrated some missing data. This was most marked on the TCQ-I, where the total score was calculated on data obtained from 38 participants (79.17% of the total sample). Although participants did not report their reasons for omitting questions, it would seem noteworthy that the TCQ-I was by far the longest questionnaire, with 43 items, which participants might have found off-putting. Participants’ comments were recorded throughout the questionnaire, and are cited below.

When completing the GHQ-12, some participants offered reasons for their symptoms, including the illness of a family member and worry regarding their own health. Two participants stated that they did not know, or couldn’t remember, the answers to questions. Similarly, on the PSQI, several participants cited influences on their sleep. These included: hospital appointments, disturbed thoughts, restless legs, concerns regarding family members, bereavement, housing difficulties, looking after a partner, needing to go to the toilet, external noise and illness, for example, trapped nerves, asthma and arthritis.
Fewer participants commented in response to the SDQ. One participant reported finding the questions difficult to read due to visual impairment. One participant reported a difference between previous and current sleep behaviour, and one participant reported completing puzzle books rather than reading or watching television. This apparent concern to provide the most accurate information possible was also apparent in participants' comments regarding the TCQ-I and DBAS-10, where comments could be interpreted as providing further detail regarding responses.

For example, another participant noted a difference between previous and current behaviour on the TCQ-I. Another participant reported focusing on positive rather than negative thoughts, and one reported engaging in particular thought control strategies on waking up during the night (presumably rather than before going to sleep). Finally, one participant noted "trying" to use several strategies and finding another "difficult". Similarly qualifying comments written in relation to the DBAS-10 included "I don't feel like doing ...", commenting that a poor night's sleep only affects the following day rather than the week, and interferes with "some not all" daily activities. Other participants omitted questions, stating that they "don't apply because I always sleep well" or "I haven't thought about that".
Discussion

Overall, the data collected were consistent with the aspects of Harvey’s (2002) cognitive model of insomnia investigated, and the stated hypotheses. They also offer additional information regarding sleep disturbances in older adults with mental health problems, and the roles of safety behaviours and dysfunctional beliefs in insomnia. This discussion will outline the study’s findings before considering their implications for Harvey’s model and for treatment, exploring the study’s strengths and limitations, and identifying questions for further research.

Main findings

Hypotheses 1 and 2: Older adults with mental health difficulties will demonstrate a significant incidence of insomnia. This will increase as the severity of mental health difficulties increases.

An overwhelming 4 out of 5 participants experienced clinically significant insomnia, as measured by the PSQI total score. The correlation between the PSQI total score and the GHQ-12 demonstrated that the incidence of insomnia increased as the severity of mental health difficulties increased. This could, in part, be attributable to an overlap of symptoms, for example disturbed sleep during a depressive illness. As correlational analyses do not determine cause and effect, further research will be needed to determine the direction of effects, i.e. whether insomnia is a consequence of or exacerbates mental health difficulties, and whether these effects are bi-directional.

The obtained GHQ-12 mean was below the cut-off point used to denote clinically significant levels of distress (Johnston et al., 1995), and less than half of all participants reported scores within the clinical range. It is possible that this represented a sampling or recruitment bias, such that service users with more severe mental health difficulty were less likely to be asked or less likely to agree to participate in the research. Alternatively, although this was not controlled and the data are therefore unavailable, it is possible that this result represents participants’ varying length of contact with the
CMHT, such that higher levels of distress were recorded closer to the time of referral and lower levels towards the time of discharge. This would be consistent with comparison to the scores obtained by Mathers et al. (1993).

By contrast, the obtained mean PSQI global score of was greater than the cut-off point used to denote clinically significant poor sleep (Buysse et al., 1989), and the majority of participants scored within the clinical range. This insomnia prevalence estimate of 79.1% is higher than the comorbidity estimates regarding insomnia and mental health problems of between 12 and 71 per cent in the adult population reported by Morin and Ware (1996). It is also higher than the prevalence estimates of clinically significant insomnia in older adults without mental health difficulties reported by Espie et al. (2000) and Fichten et al. (1998), estimating between 10 and 15 per cent and between 10 and 35 per cent respectively.

It is possible that the obtained data accurately reflect the prevalence of insomnia among older adults with mental health difficulties. However, it is likely that this figure is, at least in part, elevated by recruitment and/or sampling bias. Even though clinicians were informed that data were sought from participants with and without sleep difficulties, informal observations suggested that they were more likely to give questionnaires to service users whom they knew experienced sleep difficulty. Similarly, although the Participant Information Sheet stated that data was required from people with and without sleep difficulties, it would seem likely that service users who experienced sleep difficulties might find it more meaningful to complete the questionnaire and easier to relate to than service users who did not suffer from poor sleep.

This sample demonstrated significantly reduced PSQI total scores as compared to the adult insomniac samples with and without mental health difficulties investigated by Buysse et al. (1989). The current study did not explore participants’ subjective interpretations of their sleep yet it has been suggested that the distress associated with poor sleep, rather than poor sleep per se, defines insomnia. This finding therefore emphasises the importance of considering individuals’ subjective accounts of their
sleep experiences as well as objective quantitative data regarding insomnia. It is possible that this research identified poor sleep associated with the ageing process, as described by Morgan and Gledhill (1991) rather than insomnia, as defined by distress. Nonetheless, the degree to which results are consistent with Harvey’s model suggests that the data did reflect insomnia experiences. It will be important to conduct further research comparing both objective data and the subjective experiences of older and younger adults with sleep difficulties. The obtained difference between this sample and that from previous research (e.g. Buysse et al., 1989) also highlights the importance of investigating participants whose PSQI scores fall across the clinical range. As this comprises the majority of the scale, it might prove useful to further divide this range, into for example, mild, moderate and severe sleep disturbance.

Previous authors (e.g. Morin, Kowatch, Barry & Walton, 1993) have stated that medication tends to be the most common form of treatment for insomnia among older adults, and this has been linked with a range of possible adverse effects, including rebound insomnia, impaired cognitive functioning, memory and concentration, and problems with co-ordination and an increased risk of falls (Morin, Kowatch, Barry & Walton, 1993; Chesson et al., 1999; Morgan & Gledhill, 1991; Edinger & Wohlgemuth, 1999). It is therefore encouraging that, even with the high levels of insomnia reported, this sample’s use of medication appeared to be low. It is possible that participants had been advised against medication usage by the CMHT health professionals working with them; this would explain why this figure is reduced as compared to general population samples. Alternatively, it could relate to the suggestion above that, even though most participants’ PSQI scores fell into the clinical range, participants themselves did not define their sleep experiences as abnormal and therefore did not seek treatment. The low incidence of treatment-seeking for insomnia has been previously noted (Nutt & Wilson, 1999). Future research could usefully compare medication use, and the reasons underlying its usage, and that of other treatments, across clinical and non-clinical samples. The observed tendency for frequent use amongst participants who reported using medication to aid sleep would seem to place these participants at increased risk of adverse effects, and highlights a
need for recognition of sleep difficulties amongst the mental health professionals working with them and the availability of effective treatments.

Hypothesis 3: Insomnia will be related to increased negative cognitive activity, dysfunctional beliefs and safety behaviours.

Negative cognitive activity, as measured by the Mental Anxiety subscale of the SDQ, and dysfunctional beliefs, measured by the DBAS-10, were both significantly associated with insomnia, as measured by the PSQI total score. These relationships were both in the predicted direction, demonstrating that insomnia increased as negative cognitive activity and the extent to which dysfunctional beliefs about sleep were endorsed increased, and are consistent with Harvey’s model.

The relationship between insomnia and safety behaviours appeared to be less clear-cut. The Worry subscale of the TCQ-I was significantly associated with insomnia, as measured by the PSQI total score, and the Punishment subscale approached significance. These relationships were also in the predicted directions, i.e. increased insomnia was observed with increased use of worry and punishment, and are consistent with Harvey’s model. The other subscales of the TCQ-I - Thought Suppression, Replacement, Reappraisal and Social Control - did not demonstrate significant relationships with insomnia, as measured by the PSQI.

Overall, these results support Harvey’s model, by demonstrating that negative cognitive activity, dysfunctional beliefs and worry are all associated with insomnia. They also highlight the importance of considering individual safety behaviours, as worry appeared to be important in the maintenance of insomnia, but suppression, replacement, reappraisal and social control do not.

As Morin et al. (1993) described the need to address the influences of individual beliefs, each item of the DBAS-10 was considered in relation to insomnia as measured by the PSQI, and thereby provides further detail for Harvey’s model, by identifying particular beliefs which appear to be dysfunctional in insomnia. The most frequently
endorsed beliefs concerned needing 8 hours of sleep per night, needing naps or recovery nights, and fears regarding controllability of thoughts. There did not appear to be a clear pattern underlying dysfunctional beliefs and their relationships with other variables. For example, items 3, 6 and 9 all address daytime consequences of insomnia yet one correlated highly with insomnia as measured by the PSQI total score, one correlated moderately and one was not significant. This demonstrates a need for further research.

Hypothesis 4: Negative cognitive activity will be more closely related to insomnia than Physical Tension.

The larger correlation coefficient observed between the Mental Anxiety subscale of the SDQ as compared to the Physical Tension subscale demonstrated a stronger correlation between insomnia and negative cognitive activity than Physical Tension. This is consistent with both Harvey's model and previous research (Nicassio et al., 1985; Fichten et al., 2001). However, the magnitude of this size difference is small, and the fact that Physical Tension demonstrated a highly significant correlation with insomnia suggests that it might also be an important variable in models of insomnia.

Hypothesis 5: Safety behaviours will be related to dysfunctional beliefs about sleep.

The Worry and Punishment subscales of the TCQ-I demonstrated highly significant relationships with the DBAS-10 total score, and suppression demonstrated a moderately significant relationship. These relationships were in the predicted direction, i.e. their use increased as the extent of dysfunctional beliefs increased, and are therefore consistent with Harvey's model. Replacement, Reappraisal and Social Control did not demonstrate significant relationships with dysfunctional beliefs.
Hypothesis 6: Negative cognitive activity will be related to dysfunctional beliefs about sleep.

The obtained significant relationship between negative cognitive activity and dysfunctional beliefs is consistent with this hypothesis, and Harvey’s model. The DBAS-10 total score and eight individual items of the DBAS-10 were significantly correlated with the SDQ Mental Anxiety subscale. The exceptions to this were items 1 and 4, concerning needing 8 hours sleep per night and staying in bed when unable to sleep.

Hypothesis 7: Negative cognitive activity will be related to safety behaviours.

The TCQ-I Worry, Punishment and Replacement subscales demonstrated highly significant relationships with the Mental Anxiety subscale of the SDQ, which indicated that their use was associated with increased negative cognitive activity. The Suppression subscale demonstrated a less significant relationship with negative cognitive activity, but still indicated that its use was associated with an increase in negative cognitive activity. Reappraisal and Social Control did not demonstrate significant relationships with, and were therefore independent of this variable.

These results are therefore partially consistent with the hypothesis and Harvey’s model as it would appear that only some safety behaviours are associated with increased negative cognitive activity, namely Worry, Punishment, Replacement and Suppression.

Implications of findings for Harvey’s model

In general, Harvey’s model, which was proposed to account for sleep disturbance among adult insomniacs, also appears to explain sleep disturbance among older adults. As predicted, negative cognitive activity and dysfunctional beliefs about sleep, as measured by the Mental Anxiety subscale of the SDQ and DBAS-10 were both associated with insomnia, as measured by the PSQI. The Worry subscale of the TCQ-I was also associated with insomnia. Significant relationships were also observed
between negative cognitive activity and safety behaviours, negative cognitive activity and dysfunctional beliefs about sleep, and between dysfunctional beliefs about sleep and safety behaviours, each of which was predicted by the model. However, the results also offer information regarding specific safety behaviours, dysfunctional beliefs and apparently unconsidered variables which will now be discussed.

**Safety behaviours**

Worry was the only safety behaviour measured by the TCQ-I which correlated with all of the other variables predicted, namely insomnia, as measured by the PSQI, negative cognitive activity, measured by the Mental Anxiety subscale of the SDQ and dysfunctional beliefs measured by the DBAS-10. It would therefore seem to have the strongest relationship with sleep, and be the most relevant thought control strategy safety behaviour in Harvey’s model measured by the TCQ-I. Punishment and suppression were significantly associated with negative cognitive activity and dysfunctional beliefs, which suggests that they are important safety behaviours in this model. Similarly, replacement demonstrated a significant relationship with negative cognitive activity and is therefore also implicated in the model. By contrast, reappraisal and social control did not demonstrate significant relationships with any of the variables considered here, and would therefore seem to be less influential safety behaviours according to Harvey’s model, at least among older adults with mental health difficulties.

Although worry was the most influential thought control strategy under investigation here, it was not one of the most commonly used strategies. This contrasts with the findings of Harvey (2001) who reported that adult insomniacs most frequently engaged in worry, suppression and replacement. She noted that good sleepers tended to employ social control and replacement strategies. By contrast, the current study identified social control, replacement and suppression as the most commonly used strategies, despite the high incidence of insomnia. Further research will be necessary to determine whether this represents an age difference.
Dysfunctional beliefs about sleep

This study has provided valuable information addressing Morin et al.'s (1993) suggestion that it is important to consider the importance of individual beliefs as well as the overall DBAS score. Whilst the DBAS-10 total score was significantly correlated with insomnia, negative cognitive activity and safety behaviours, individual items were found to correlate differently with different variables. Most items correlated with both negative cognitive activity and insomnia, but some did not. Within negative cognitive activity, items 1 and 4 did not demonstrate significant relationships; these beliefs referred to needing 8 hours sleep to feel refreshed and function well during the day, and the belief that it is important to stay in bed when unable to sleep. Items 2, 4 and 9 did not demonstrate significant relationships with insomnia; items 2 and 9 relate to needing recovery nights and having no energy or being unable to function well after being unable to sleep the night before.

Morin et al.'s emphasis on the importance of considering individual beliefs is highlighted here, but the apparent overlap of beliefs between items which had contrasting relationships with other variables, e.g. items 9, mentioned above, and 6, which refers to poor sleep interfering with daily activities the next day, infers that further research is necessary to explore the relationships between such beliefs and the meanings attributed to them by participants. To conclude this section, Harvey's inclusion of dysfunctional beliefs in her model has been supported, but a need for further clarification regarding which beliefs are particularly important has been identified.

Additional variables

The highly significant relationship between insomnia, measured by the PSQI, and mental health status, measured by the GHQ-12, demonstrates that mental health status might be an important variable in models of insomnia. The direction of the relationship was in the predicted direction, i.e. insomnia increased as the severity of mental health
disturbance increased. Although the relationship between insomnia and mental health disturbance has been widely documented (e.g. Morin & Ware, 1996; Mellinger et al., 1985; Ohayon et al., 1998), this research suggests that mental health might be an important factor even when, as with the majority of this population, GHQ-12 scores are within the normal range.

Comparison of the correlation coefficients obtained between insomnia, measured by the PSQI, and the SDQ mental arousal and Physical Tension subscales, demonstrated that negative cognitive activity was more closely related to insomnia. However, Physical Tension also demonstrated a highly significant relationship, which suggests that it might be an important component to include in models of insomnia. Further research will be necessary to determine whether physical tension, and mental health status, have predominantly causal or consequential relationships with insomnia.

**Implications of findings for treatment**

Harvey's (2002) treatment recommendations are to: “reduce selective attention and monitoring for sleep-related threat cues, correct distorted perception of sleep and daytime deficits, correct erroneous beliefs about sleep, and eliminate the use of counter-productive safety behaviours” (Harvey, 2002, p.884) and she advocates using outcome measures which look at both sleep and daytime functioning. The part of the model from which her first two suggestions derive was not under investigation here, so will not be discussed.

This study certainly indicated that employing methods to decrease negative cognitive activity, safety behaviours and dysfunctional beliefs is likely to be helpful in the treatment of insomniacs. In particular, reducing the use of worry, punishment and suppression as thought control strategies would seem to be useful, and could be incorporated into a cognitive framework via education and consideration of techniques used with other psychological disorders where necessary, e.g. Wells et al.’s consideration of social phobia (1995) and Ehlers and Clark’s work with post-traumatic stress disorder (1999). Davey, Tallis and Capuzzo (1996) describe the importance of
considering underlying beliefs about worry, as these influence its relationships with other variables. It will also be important to identify the particular dysfunctional beliefs that insomniacs endorse, whether these are included in the DBAS-10 or identified from other sources, in order to make any treatment relevant to the individual. Again, methods of addressing dysfunctional beliefs have been discussed in relation to other psychological disorders, including obsessive-compulsive disorder (Salkovskis, 1999).

The relationships identified in this research between insomnia and physical tension and mental health status demonstrate that these may also be important areas for intervention. Relaxation training would seem likely to offer a valuable method by which to address physical tension within a cognitive-behavioural intervention, whilst effectively and appropriately addressing mental health difficulties will depend upon comprehensive assessment of an individual’s needs.

Strengths and limitations of the study

Generalisability of findings

The recruitment response rate was 27%; as data were not collected regarding non-respondents, it is difficult to ascertain the sample’s generalisability. It has also been difficult to compare the sample to the total CMHT sample, as only limited data regarding referrals to the team are collected. Nonetheless, it is striking that all participants described their ethnic origin as “White”; cross-cultural research has not yet established the influence of ethnicity or culture, e.g. insomnia experiences where afternoon naps, or siestas, are common. Related to this is the observation that only 2 participants stated that their country of origin was outside the UK, which further limits generalisability. Chevalier et al. (1999) report differing rates of insomnia even between Northern European countries, ranging from 4% in Germany to 22% in the UK.

It is noteworthy that 40 (83.3%) participants were female; this appeared to reflect a disproportionate tendency for women to be referred to the CMHTs. The study did not control for length or type of contact with CMHT professionals, although available data
demonstrated a range from 0 to 6 years since first appointment, and whether this had addressed sleep and/or other mental health difficulties, and its influence on sleep-related variables. Data were also not collected regarding participants’ reasons for referral to the CMHT, or presenting problem(s). However, discussion with team members revealed that the majority of clients referred who do not have a dementing illness tend to suffer from depression or anxiety disorders, whilst personality, bipolar and psychotic disorders are less common. Future research could usefully look at relationships between insomnia and different mental health diagnoses amongst this population. This might investigate Morin’s (1993) prediction that sleep-onset insomnia is more common amongst people with anxiety disorders, and sleep-maintenance insomnia more common among those with depressive disorders.

Regenstein (1980) and Rybarczyk and Lopez (1999) describe increasing heterogeneity among older adult samples, and suggest that research should be conducted using more specific age ranges. However, the age ranged adopted in this study is consistent with the cut-off point used to organise services in the UK, so the sample can therefore be seen as broadly representative of older adults seeking help for mental health difficulties. Although the information letter, consent form and questionnaire were printed in larger font, it is possible that this did not enable service users with visual impairments to participate in the study. This could easily be addressed in future research.

Limitations and areas beyond the scope of the current research

The most significant limitation of the study was its relatively small sample size; it will be important for future research to include larger samples, particularly as this will allow regression analyses, which will enable variables to be predicted, in line with Harvey’s model. As with any research study, there were several areas which were outside the relatively specific area of interest. It is important to make clear that there are aspects of Harvey’s model which the current study did not investigate. It will be important for future research to consider arousal and distress, selective attention and monitoring and distorted perception of deficit, including their relationships with
dysfunctional beliefs, negative cognitive activity and safety behaviours. Within the consideration of safety behaviours, the TCQ-I examines thought control strategies; there may well be additional safety behaviours engaged in by insomniacs, old and young. Harvey (2002) suggests that insomniacs tend to stay in bed when unable to sleep, a counter-productive strategy that could be examined as a safety behaviour. Wicklow and Espie (2000) reported that adult insomniacs engage in rehearsal, planning and problem-solving to address negative cognition; such observations require further investigation. In addition, the observation of Fichten et al. (2001) that positive cognitions were the most common cognitions during the pre-sleep period requires replication with an older sample and further investigation into the role played by such cognitions. Research is also needed to compare day- and night-time functioning, perhaps using the processes proposed by Harvey’s model. Harvey acknowledges that the model relates only to the maintenance of insomnia, and not its onset and suggests that developments in this area could enable the development of preventative strategies.

In addition, the study did not control for medical conditions which might have influenced sleep, for example cramp, restless leg syndrome and obstructive sleep apnoea, which is more common among older adults (Morgan & Gledhill, 1991). This could readily be addressed in future research via the inclusion of a physical complaints scale. The research also did not distinguish primary and secondary insomnia or consider the subtypes described in the ICSD criteria. Further research might elucidate whether the variables associated with insomnia differ according to its typology.

Further information might also have been gained by comparing the obtained data with that from a control group. As the sample differed from Harvey’s intended population by both their age and mental health status, comparison between this population and either older adults without mental health difficulties or younger adults with mental health difficulties would enhance the design of the study and provide further support for its conclusions. It will also be important for future research to include service users with dementia, who comprise an important proportion of the older adult population (Davison & Neale, 1996). Clinicians’ judgements were used to exclude service users with dementia; a more reliable diagnosis would have been obtained via screening all
participants, using a tool such as the Mini-Mental State Examination (MMSE; Folstein, Folstein & McHugh, 1975). The significantly increased age of the total CMHT population compared to the obtained sample could be seen to be an effect of the increased incidence of dementia with age (Davison & Neale, 1996), such that older service users were more likely to be excluded from the study due to dementia.

As mentioned above, the obtained sample size did not provide sufficient power for regression analyses to be conducted, which could have provided valuable information regarding the direction of effects. In addition, the reduced power coefficient calculated for the obtained sample also infers that the results must be treated with caution. The use of correlational analyses does not allow causality to be assumed, which will be an important area for future research to address.

In order for Harvey’s model to be of clinical, as well as theoretical, value, it will be necessary to conduct randomised controlled trials of treatments for insomnia with different client groups, including those with comorbid mental health difficulties, who constitute a considerable proportion of the insomnia population. Such work could usefully use the approaches advocated by Harvey as well as other authors. Wicklow and Espie (2000) for example describe a treatment model of insomnia which aims to reduce cognitive arousal without considering beliefs about sleep. Morin and Ware (1996) suggest that identifying the direction of effects between insomnia and its associated variables will facilitate the most effective treatment planning. For example, their observation that the onset of insomnia is frequently associated with stressful life events has not been subjected to scientific study; this might identify another valuable avenue for treatment.

Lacks and Morin (1992) suggest that insomnia is the result of a complex interaction of variables, which identifies the need to consider variables outside of the cognitive-behavioural framework. Similarly, Edinger and Wohlgemuth (1999) advocate research to evaluate the efficacy of combinations of treatments, for example medication and behavioural therapy. In addition, Edinger et al.’s (1992) observation that CBT for insomnia led to an improved sense of control over sleep and improved daytime
functioning encourages researchers and clinicians to incorporate broader treatment goals than a mere increase in sleep duration, and researchers to investigate which are the most important outcome variables.

Although individual items on the DBAS-10 were correlated with insomnia, as measured by the PSQI, and negative cognitive activity, measured by the Mental Anxiety subscale of the SDQ, analysis of correlations with the TCQ-I subscales was not conducted, as there is no existing literature to relate this to. Nonetheless, it was felt that correlating individual DBAS-10 items with insomnia and negative cognitive activity was a valuable preliminary step in the investigation of the roles of individual dysfunctional beliefs.

**Issues relating to assessment**

As noted in the introduction, the reliability and validity of the TCQ-I are currently under investigation (Harvey 2003, personal communication) which suggests that data should be interpreted cautiously, especially as it was devised with an adult, rather than an older adult, sample. Caution should also be applied to the SDQ results, as the author has been unable to find an example of its use with older adults. Space constraints did not permit consideration of each of the PSQI subscales, focusing instead on the global score. It is possible that different relationships might have been observed between, for example, sleep latency and sleep disturbances. By including an item which relates to sleep (question 2), it is possible that the GHQ-12 confounded results relating to mental health difficulty and insomnia. As the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1993) does not include items which ask directly about sleep, and is not confounded by the presence of physical symptoms, this would seem to be a valuable measure to include in any replication of this work. In addition, Johnston et al. (1995) state that the GHQ-12 measures "non-psychotic psychiatric disorder" which is problematic due to the potential inclusion of participants with psychotic symptoms. However, given the infrequency of referrals to the CMHT for individuals with psychotic symptoms, this was felt to be an acceptable risk. Although GHQ-12 scores were treated as uni-dimensional, some authors have argued
that, like the longer versions of the GHQ, it actually measures different aspects of mental health (Martin, 1999; Cheung, 2002) which questions the validity of its global score. Finally, although it is important to acknowledge that the use of self-report questionnaires might have introduced a retrospective bias (Fichten et al., 2001) that might have been reduced by using PSG methods or sleep logs, it was felt that their use would enhance recruitment by placing fewer demands on participants.

Questions for further research

There remain many questions about insomnia which warrant further research. Directly related to the current study, it is not known whether participants had discussed their sleep with the professional(s) working with them, and what, if any, advice they had received. It would also be helpful to investigate sampling and recruitment bias, by comparing respondents and non-respondents. Another important area to include is participants’ own accounts of their sleep; the majority of participants in this study scored within the clinical range of the PSQI, but attempts were not made to ascertain whether they labelled their sleep experiences as abnormal. It will also be useful for future research to study the 7 subscales of the PSQI, to ascertain whether they demonstrate the same relationships with the other variables investigated and the PSQI total score. It will also be valuable to investigate the incidence and influence of medical conditions which have the potential to influence sleep, explore different subtypes of insomnia, and consider its onset. Finally, research which assesses the direction of effects will be very important, especially where this is able to counter-act the additional time spent awake by insomniacs in the consideration of negative cognitive activity and safety behaviours.

There are also aspects of Harvey’s model which require further research with this population. These include: selective attention and monitoring, arousal and distress and distorted perceptions of deficit. It will also be important to identify and investigate other safety behaviours and explore the influence of mental health status and physical tension, which this study suggested are important. Although Harvey’s model delineates day- and night-time processes, daytime processes do not appear to have been the focus
of any published research. This corresponds to Edinger et al.'s (1992) suggestion that it is important to consider other outcomes, for example, daytime functioning, in addition to sleep-related variables. Although dysfunctional beliefs about sleep were demonstrated by this research to be related to both insomnia and other aspects of Harvey's model, the role and influence of individual beliefs yielded rather complex results. It will therefore be important to identify and explore the relationships between a range of sleep-related beliefs.

Although all participants were aged 65 or above and therefore represent a sample of Older Adult CMHT service users, they can still be seen to represent a heterogeneous group, due to the broad age range. Future research could usefully explore differences according to gender, ethnicity or diagnosis, including service users with dementia. Regenstein (1980) also recommends looking at smaller age ranges, although it is important to consider the practical value of this.

Two important areas for further research focus on treatment for insomnia. This will incorporate some of the areas already mentioned, for example, considering the process by which service users label their sleep abnormal, and thereby, needing treatment, in addition to exploring health professionals' knowledge regarding insomnia and the availability of treatment. Treatment outcome studies could usefully explore different aspects of Harvey's model and the reasons underlying service users' decision to seek treatment, and which sort of treatment. Due to the adverse effects related to its use, it will be important for research in this area to include medication. Lastly, the observation that the majority of participants scored within the clinical range of the PSQI implies that it might be useful to further subdivide this scale, into for example, mild, moderate and severe disturbance.
Conclusions

This study investigated the applicability of aspects of Harvey’s cognitive model of insomnia to the insomnia experiences of older adults with mental health difficulties. The majority of the sample scored within the clinical range of the PSQI, suggesting clinically significant insomnia. DBAS-10 global scores and the SDQ Mental Anxiety and TCQ-I Worry subscales, demonstrated significant relationships with insomnia, as measured by the PSQI global score. Significant relationships were also observed between negative cognitive activity, dysfunctional beliefs and the Worry, Suppression, Replacement and Punishment subscales of the TCQ-I, and between Suppression, Punishment, Worry and dysfunctional beliefs. These were all in the predicted directions, and consistent with Harvey’s model.

Additional variables which demonstrated significant relationships were the Physical Tension subscale of the SDQ and mental health status, as measured by the GHQ-12. These would therefore seem to also play important roles in the maintenance of insomnia. Overall, the results suggest that the treatment recommendations made by Harvey in relation to work with adult insomniacs will also be useful for older adults with mental health difficulties and insomnia, i.e. reducing negative cognitive activity, eliminating counter-productive safety behaviours, and identifying and addressing dysfunctional beliefs about sleep. It may also prove important to address physical tension and mental health difficulties.
References


and post-traumatic stress to potential sleep disorders in sexual assault survivors with nightmares, insomnia and PTSD. *Journal of Traumatic Stress, 14*, 4, 647-665.


## Appendix

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Appendix A: DSM-IV criteria for insomnia (American Psychiatric Association, 1994)

a. The predominant complaint is difficulty initiating or maintaining sleep, or nonrestorative sleep, for at least 1 month.

b. The sleep disturbance (or associated daytime fatigue) causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.

c. The sleep disturbance does not occur exclusively during the course of Narcolepsy, Breathing-Related Sleep Disorder, Circadian Rhythm Sleep Disorder, or a Parasomnia.

d. The disturbance does not occur exclusively during the course of another mental disorder (e.g. Major Depressive Disorder, Generalised Anxiety Disorder, a delirium).

e. The disturbance is not due to the direct physiological effects of a substance (e.g. a drug of abuse, a medication) or a general medical condition.
Appendix E: Participant Information Sheet and Consent Form
Invitation to participate in research about sleep

Please read this information carefully. It will explain the research that is being carried out and what it involves. Please take your time to decide whether or not to take part. You may discuss it with other people or myself if anything is not clear or if you would like more information.

You will now see questions and answers about the research.

1. Why is the research being carried out?

A lot of research has looked at sleep problems and insomnia to try to understand why they happen. One view suggests that people’s thoughts about sleep might be responsible. This view has been tested with adults aged under 65, but different factors might be involved among people of different ages. Other studies have not looked at sleep problems in people with other difficulties. Therefore, this study will look at the sleep problems of adults aged over 65 who have been referred to mental health services.

2. Why have I been chosen?

You may or may not suffer with disturbed sleep, this project needs information from both groups of people. Most people who come to the older people’s mental health teams at Redhill and Epsom will be invited to take part. I hope that more than 100 people will take part so that the findings are relevant to lots of people.

3. Do I have to take part?

No, you can decide whether or not to take part. If you do decide to take part, you will need to sign the consent form in this pack. You can keep this information. You can change your mind about taking part at any time, and
you will not be asked to give a reason. Deciding not to take part in the study will not affect your care.

4. What will happen to me if I take part?

You will be asked to complete a questionnaire. You can choose whether to complete the questionnaire in this pack, and post it back to me with your consent form, or you can post me your consent form and then I will contact you, so that you can complete the questionnaire with me over the telephone. I am providing Freepost envelopes for you to return your consent form and questionnaire.

The questionnaire will ask your age, gender and ethnic origin. There will then be five sections, one about how well you feel, and four about different aspects of your sleep and your thoughts about sleep. You can leave out any questions you don’t want to answer. The questionnaires take about half an hour to complete.

5. What are the possible disadvantages and risks of taking part?

Your treatment will not be affected by whether you take part in this study or not. The information that you give will not be available to anybody working with you. If you find any part of the study distressing, you can meet with me to discuss it and, if necessary, I will ensure that you receive continuing support.

6. What are the benefits of taking part?

The study is not designed to influence your treatment, but the information learnt may help future treatment for sleep disturbances.

7. What if something goes wrong?

If you are unhappy with any part of the study at any time, you can discuss this with me and I will not include the information you have given me in the study. I can also give you information about the National Health Service complaints procedure.

8. Will my information be kept confidential?

All data will be handled in accordance with the Data Protection Act 1998. The information which I collect from you will be strictly confidential and will be kept locked in a secure office. The questionnaire will not ask for your name or address. I will use a number to link your questionnaire to your consent form, so that I can find your questionnaire if you decide to
withdraw from the study. I will be the only person who has access to these numbers.

As the study is not designed to affect your treatment, there is usually no need for me to tell anyone whether or not you take part in the study. The only time I would have to tell somebody about you taking part in the project, and give them information which you have given me, is if you tell me something which makes me worry about your safety or the safety of people around you. I will tell you if this happens.

9. What will happen to the results of the research?

My report will be submitted to the University of Surrey, as it forms part of my training in clinical psychology. No-one will be identified by name or other details. A summary of the results will be available from the Redhill and Epsom mental health services for older adults.

10. Who has reviewed the research?

The research has been approved by the University of Surrey and East Surrey Local Research Ethics Committees.

11. What do I do if I want more information?

You can contact me or my supervisor to discuss any aspect of the project. My contact details are listed above. You may contact Mr Ron Bracey, Consultant Clinical Psychologist, via Hazelwood Unit, East Surrey Hospital, Redhill, Surrey, RH1 5DE, or on telephone 01737 231806.

12. What happens now?

If you would like to take part and you don’t want to complete the questionnaire over the telephone, please sign the attached consent form, complete the questionnaire and return them both to me in the Freepost envelope. If you would like to complete the questionnaires over the telephone, please show this on your consent form and return it to me in the Freepost envelope. I will then contact you as you request. You can keep this information for future reference. When I receive your consent form, I will make a copy of it for you to keep.

Thank you for taking the time to read this information.

Signed: Jennifer Weall

Researcher's name: Jennifer Weall       Date: 9th June 2003

Consent form: research about sleep

Please read the information and tick the appropriate boxes.

<table>
<thead>
<tr>
<th>I have read the information sheet dated 9th June 2003. I know I can contact Jennifer Weall for more information.</th>
</tr>
</thead>
<tbody>
<tr>
<td>I know it is my choice whether to take part in this research. I can change my mind at any time, without giving a reason. My care will not be affected.</td>
</tr>
<tr>
<td>I understand that information I give will be confidential and anonymous. No-one apart from Jennifer Weall will know whether I take part. No-one will be able to identify me from the information I give.</td>
</tr>
<tr>
<td>I agree to take part in this study.</td>
</tr>
</tbody>
</table>

If you would like to take part in the study, please tick one of these boxes:

<table>
<thead>
<tr>
<th>I will complete the questionnaire and send it to you.</th>
</tr>
</thead>
<tbody>
<tr>
<td>I would like to complete the questionnaire over the telephone. My telephone number is:</td>
</tr>
</tbody>
</table>

The most convenient days and times for me are:

Signed: ____________________________ Date: ____________________________

Name: ____________________________

Researcher’s signature: ____________________________ Date: 9th June 2003

Thank you for your time.

Please return this form in the Freepost envelope provided.
Appendix F: Questionnaire
Thank you for agreeing to take part in this research.
Remember you can contact me if you have any questions about it.

Please work your way through the questions in this pack, reading the questions carefully and choosing the answers which most apply to you. It should take about half an hour to complete. Please leave out any questions you do not wish to answer.

Please return the questionnaire in the Freepost envelope when you have finished.
Part 1: Demographic Information

Please tick the correct box to show your gender:

<table>
<thead>
<tr>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
</table>

Please write your current age  .......... years

Please tick to show your country of birth:

<table>
<thead>
<tr>
<th>England</th>
<th>Scotland</th>
<th>Wales</th>
<th>Northern Ireland</th>
<th>Irish Republic</th>
<th>Elsewhere</th>
</tr>
</thead>
</table>

*If elsewhere, please write the name of the country below:*
Now please tick to show your ethnic group:

*If you are descended from more than one ethnic or racial group, please tick the group to which you consider you belong, or tick 'Any other racial group' and describe your ancestry in the space provided.*

<table>
<thead>
<tr>
<th>White</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black - Caribbean</td>
</tr>
<tr>
<td>Black - African</td>
</tr>
<tr>
<td>Black - Other</td>
</tr>
</tbody>
</table>

*If Black - Other, please describe below:*

<table>
<thead>
<tr>
<th>Indian</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pakistani</td>
</tr>
<tr>
<td>Bangladeshi</td>
</tr>
<tr>
<td>Chinese</td>
</tr>
<tr>
<td>Any other racial group</td>
</tr>
</tbody>
</table>

*If 'any other racial group', please describe below:*
Part 2: Questions about health, sleep and thought processes

Section A: I should like to know if you have had any medical complaints and how your health has been in general, over the last few weeks. Please answer the questions by ticking the box underneath the answer which you think most applies to you. Remember that I want to know about present and recent complaints, not those that you had in the past.

Have you recently ...

<table>
<thead>
<tr>
<th>1. been able to concentrate on whatever you’re doing?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Better than usual</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2. lost much sleep over worry?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3. felt like you’re playing a useful part in things?</th>
</tr>
</thead>
<tbody>
<tr>
<td>More so than usual</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4. felt capable of making decisions about things?</th>
</tr>
</thead>
<tbody>
<tr>
<td>More so than usual</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5. felt constantly under strain?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
</tr>
</tbody>
</table>
6. felt you couldn’t overcome your difficulties?

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>No more than usual</th>
<th>Rather more than usual</th>
<th>Much more than usual</th>
</tr>
</thead>
</table>

7. been able to enjoy your day-to-day activities?

<table>
<thead>
<tr>
<th></th>
<th>More so than usual</th>
<th>Same as usual</th>
<th>Less so than usual</th>
<th>Much less than usual</th>
</tr>
</thead>
</table>

8. been able to face up to your problems?

<table>
<thead>
<tr>
<th></th>
<th>More so than usual</th>
<th>Same as usual</th>
<th>Less so than usual</th>
<th>Much less able</th>
</tr>
</thead>
</table>

9. been feeling unhappy and depressed?

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>No more than usual</th>
<th>Rather more than usual</th>
<th>Much more than usual</th>
</tr>
</thead>
</table>

10. been losing confidence in yourself?

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>No more than usual</th>
<th>Rather more than usual</th>
<th>Much more than usual</th>
</tr>
</thead>
</table>

11. been thinking of yourself as a worthless person?

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>No more than usual</th>
<th>Rather more than usual</th>
<th>Much more than usual</th>
</tr>
</thead>
</table>

12. been feeling reasonably happy, all things considered?

<table>
<thead>
<tr>
<th></th>
<th>More so than usual</th>
<th>About the same as usual</th>
<th>Less so than usual</th>
<th>Much less than usual</th>
</tr>
</thead>
</table>
Section B: The following questions relate to your usual sleep habits during the past month only. Your answers should indicate the most accurate reply for the majority of days and nights in the past month.

During the past month:

<table>
<thead>
<tr>
<th>Question</th>
<th>Response Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>What time have you usually gone to bed?</td>
<td></td>
</tr>
<tr>
<td>How long (in minutes) has it taken you to fall asleep each night?</td>
<td></td>
</tr>
<tr>
<td>When have you usually got up in the morning?</td>
<td></td>
</tr>
<tr>
<td>How many hours of actual sleep have you got at night? (This may be different from the number of hours you spend in bed)</td>
<td></td>
</tr>
</tbody>
</table>

During the past month, how often have you had trouble sleeping because you:

<table>
<thead>
<tr>
<th>Issue</th>
<th>Not during the past month</th>
<th>Less than once a week</th>
<th>Once or twice a week</th>
<th>Three or more times a week</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Cannot get to sleep within 30 minutes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. Wake up in the middle of the night or early morning</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c. Have to get up to use the bathroom</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d. Cannot breathe comfortably</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e. Cough or snore loudly</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>f. Feel too cold</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>g. Feel too hot</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>h. Have bad dreams</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>i. Have pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
During the past month, how often have you:

<table>
<thead>
<tr>
<th>j. Had trouble sleeping for other reason(s), please describe, including how often you had trouble sleeping because of this reason(s)</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>How often have you taken medicine (prescribed or 'over the counter') to help you sleep?</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>How often have you had trouble staying awake while driving, eating meals, or engaging in social activity?</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>How much of a problem has it been for you to keep up enthusiasm to get things done?</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>During the past month, how would you rate your sleep quality overall?</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Not during the past month</th>
<th>Less than once a week</th>
<th>Once or twice a week</th>
<th>Three or more times a week</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Very good</th>
<th>Fairly good</th>
<th>Fairly bad</th>
<th>Very bad</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Very good</th>
<th>Very bad</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Section C: Please tick the box for the response which shows how true each statement is for your typical sleep pattern.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Never true</th>
<th>Seldom true</th>
<th>Sometimes true</th>
<th>Often true</th>
<th>Very true</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I can't get into a comfortable position in bed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. My mind keeps turning things over</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. I can't get my sleep pattern into a proper routine.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. I get too &quot;worked up&quot; at not sleeping</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. I find it hard to physically &quot;let go&quot; and relax my body</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. My thinking takes a long time to &quot;unwind&quot;</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. I don't feel tired enough at bedtime</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>8. I try too hard to get to sleep</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. My body is full of tension</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. I am unable to empty my mind</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. I spend time reading/watching TV in bed when I should be sleeping</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. I worry that I won't cope tomorrow if I don't sleep well</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Section D: Many people find that as they are trying to get to sleep at night thoughts relating to the day they have just had or thoughts about tomorrow come to mind. Other times thoughts relating to ongoing problems or stressors at work or in your home life come to mind. Sometimes these thoughts make it hard to fall asleep.

How often does thinking too much keep you awake?

0 1 2 3 4 5 6 7 8 9 10
Never Every night

Below are a number of things that people do to control these thoughts. Please read each statement carefully and tick the box to indicate how often you use each technique to control the thoughts that run through your mind as you are trying to get to sleep at night. There are no right or wrong answers. Do not spend too much time thinking about each one.

When thoughts running through my mind keep me awake at night ....

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I tell myself not to think about them now</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. I try to push the thoughts out of my head</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. I count sheep</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. I call to mind positive images instead</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. If the thoughts relate to a problem I make a decision about it in order to solve the problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. I try to block them out by reading a book, watching TV or listening to the radio</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
<td>Almost always</td>
</tr>
<tr>
<td>---</td>
<td>------</td>
<td>-----------</td>
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<td>---------------</td>
</tr>
<tr>
<td>7. I ruminate about them</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>8. I decide to put them “on hold” until the morning</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. I get out of bed and write about them</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. I let my mind go blank</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. I tell myself not to be so stupid</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. I focus on the thought</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. I replace the thought with a more trivial bad thought</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. I don’t talk about the thought to anyone</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. I punish myself for thinking the thought</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. I dwell on other worries</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. I keep the thought to myself</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. I think about something else instead</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. I challenge the thought’s validity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. I get angry at myself for having the thought</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21. I avoid discussing the thought</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22. I shout at myself for having the thought</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>23. I analyse the thought rationally</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>24. I slap or pinch myself to stop the thought</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25. I think pleasant thoughts instead</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>26. I find out how my friends deal with these thoughts</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>27. I worry about more minor things instead</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>28. I do something I enjoy</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>29. I try to reinterpret the thought</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
<td>Almost always</td>
</tr>
<tr>
<td>---</td>
<td>-------</td>
<td>-----------</td>
<td>-------</td>
<td>---------------</td>
</tr>
<tr>
<td>30.</td>
<td>I occupy myself with work instead</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>31.</td>
<td>I think more about the more minor problems I have</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>32.</td>
<td>I try a different way of thinking about it</td>
<td></td>
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<td>33.</td>
<td>I think about past worries instead</td>
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<td>34.</td>
<td>I ask my friends if they have similar thoughts</td>
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<td>35.</td>
<td>I focus on different negative thoughts</td>
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<td>36.</td>
<td>I question the reasons for having the thought</td>
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<td>37.</td>
<td>I tell myself that something bad will happen if I think the thought</td>
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<td>38.</td>
<td>I talk to a friend about the thought</td>
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<td>39.</td>
<td>I keep myself busy</td>
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<td>40.</td>
<td>I prefer to think things through than distract from them</td>
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<td>41.</td>
<td>I seek reassurance from others (e.g. my bed partner or a friend the following day)</td>
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<td>42.</td>
<td>I say &quot;stop&quot; to myself</td>
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<td>43.</td>
<td>I do something physical to block them (e.g. turn over, get out of bed)</td>
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Section E: Please indicate to what extent you personally agree or disagree with each of the statements listed below. There is no right or wrong answer. For each statement, place a mark ( / ) along the line wherever your personal rating falls. Try to use the whole scale, rather than placing your marks at one end of the line.

1. I need 8 hours of sleep to feel refreshed and function well during the day.

   Strongly disagree .......................................................... Strongly agree

2. When I don't get a proper amount of sleep on a given night, I need to catch up on sleep the next day by napping or on the next night by sleeping longer.

   Strongly disagree .......................................................... Strongly agree

3. I am concerned that chronic insomnia may have serious consequences for my physical health.

   Strongly disagree .......................................................... Strongly agree

4. When I have trouble getting to sleep, I should stay in bed and try harder.

   Strongly disagree .......................................................... Strongly agree

5. I am worried that I may lose control over my abilities to sleep.

   Strongly disagree .......................................................... Strongly agree
6. After a poor night's sleep, I know that it will interfere with my daily activities on the next day.

Strongly disagree —— Strongly agree

7. When I feel irritable, depressed, or anxious during the day, it is mostly because I did not sleep well the night before.

Strongly disagree —— Strongly agree

8. When I sleep poorly on one night, I know it will disturb my sleep schedule for the whole week.

Strongly disagree —— Strongly agree

9. When I feel tired, have no energy, or just seem not to function well during the day, it is generally because I did not sleep well the night before.

Strongly disagree —— Strongly agree

10. I get overwhelmed by my thoughts at night and often feel I have no control over my racing mind.

Strongly disagree —— Strongly agree

Thank you for taking part in this research and answering these questions.

Please return your answers to me using the Freepost envelope.
Appendix G: Summary of results available to participants
Sleep research - summary of results

Thank you for taking part in this study. This information will tell you a little bit more about the aims of the project, who took part and what the results indicated.

1. What was the research investigating?

In 2002, Allison Harvey devised a model of insomnia to explain insomnia among adults. She suggested that people's beliefs about sleep (for example, believing that they must have 8 hours sleep at night to function well during the day), behaviour when they are unable to sleep (for instance, the ways that they try to control their thoughts) and their negative thought processes all affect sleep. This is helpful for professionals working with people with insomnia, as it suggests ways they might help people to sleep better. My study examined whether Harvey's model also explains insomnia among older people with mental health difficulties, to see whether the same methods of improving sleep might be helpful.

2. Who took part in the study?

48 people took part in the study. They had all been referred to Redhill or Epsom Community Mental Health Teams for Older Adults.

3. What did the results show?

The results showed that most people who took part in the study had difficulty sleeping. They also showed relationships between the different factors which were investigated (beliefs about sleep, behaviour when unable
to sleep and negative thought processes) which were predicted by Harvey’s model. Sleep difficulty was related to each of the factors mentioned above, such that people had more difficulty sleeping when they also had unhelpful beliefs about sleep, were worried about not sleeping or punished themselves for not sleeping, and when they were distressed about not sleeping. There was also a relationship between sleep and mental health, such that the more severe someone’s mental health difficulty was, the more severe their sleep difficulty appeared to be.

4. What will happen to the results now?

The research project has been written up and submitted to the University of Surrey, as it fulfils part of the Clinical Psychology training programme requirements. The results have also been discussed with staff working in the Community Mental Health Teams for Older Adults, to help them understand more about sleep difficulties with people they work with.

5. What do I do if I want more information about sleep problems or this project?

You can contact me using the details at the top of this information before the end of December 2003, or you can speak to the person you work with at the Community Mental Health Team.

Thank you again for your interest in this work.

With best wishes,

Signed: [Signature]

Researcher’s name: Jennifer Weall Date: 18th October 2003
Participants’ summary of results dated: 18th October 2003, version 1.