A Portfolio of Study, Practice and Research Work

Anxiety and depression in breast cancer survivors: the role of illness perceptions

Volume I

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By
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Academic

Dossier
"Is cognitive therapy an efficacious treatment for psychoses?"

Long Term Disabilities Essay
February 1998
Year I
Introduction

DSM-IV (1994) describes a range of symptoms of psychosis. Diagnosis is made following the assessment of a complex pattern, usually involving disturbance in several of the following areas: content and form of thought, perception, sense of self, affect, relation to the external world, and psychomotor behaviour (Roth and Fonagy, 1996). A distinction is often made clinically between positive (acute) symptoms such as delusions and hallucinations and negative (residual) symptoms such as social disability and emotional disturbance (such as feelings of severe anxiety, despair, loneliness or unworthiness). The disorder is frequently long term, although some people experience one or two episodes, after which they recover fully.

The Epidemiological Catchment Area program reports one month prevalence rates for schizophrenia of 60 per 10,000 and lifetime prevalence rates of 130 per 10,000 in the United States (Reiger, Boyd & Burke 1988). This indicates the sizeable number of individuals who are likely to experience a psychotic disorder.

Drug Treatment for Psychosis

Neuroleptic medication is widely recognised as the treatment of choice, at least in the active phases of the disorder. Such medication has a beneficial effect for many people in the acute phase. However, some people do not respond favourably to neuroleptic medication. For example, Lieberman, Mayerhoff and Loebel (1991) report that approximately 14% of people in their first episode of schizophrenia did not respond adequately to neuroleptic medication, and of those who had experienced previous episodes of schizophrenia, at least 25% failed to respond. Moreover, other individuals continue to experience distressing and disabling positive symptoms despite taking appropriate levels of medication. Curson, Barnes, Bamber, Platt, Hirsch and Duffy (1985) reported that 23% of their sample diagnosed with schizophrenia, reported positive symptoms seven years after discharge from hospital despite compliance with neuroleptic medication.
In a review of treatment approaches to schizophrenia, Roth and Fonagy (1996) conclude that the symptoms of schizophrenia are effectively treated by neuroleptics in 50% to 75% of individuals. Therefore, between 50% and 25% of individuals with psychosis will not be effectively treated. This indicates a clear need to utilise additional therapeutic approaches in the treatment of psychosis, as conventional treatments do not lead to complete remission in symptoms for many.

Furthermore, compliance with neuroleptic medication is an issue. Curry (1985) reports that between 20 and 65 per cent of individuals taking such medication discontinue its use. It is widely accepted that neuroleptic medication can lead to unpleasant physical side effects such as tardive dyskinesia, the effects of which may be irreversible (British Medical Association, 1994).

**Cognitive therapy for Psychosis**

The application of cognitive behavioural techniques to the management of problems of people with psychoses is a relatively new development (Fowler, Garety & Kuipers, 1995).

One of the first reported cognitive approach to the treatment of positive symptoms of psychosis was described by Watts, Powell and Austin (1973). Their intervention (belief modification) avoided a confrontational approach and aimed to use sensitive questioning of the evidence underlying delusional beliefs.

Cognitive behavioural approaches have built on this early work, encouraged by research indicating that the belief modification approach was more efficacious than confrontational approaches in the long term (Milton, Patwa and Hafner, 1978).

Cognitive therapy for psychosis typically has three aims, first to reduce residual positive symptoms, second to reduce emotional disturbance and finally to encourage the
individual to become involved in regulating the risk of social disability and relapse (Fowler et al, 1995). Fowler et al (1995) divide the process of cognitive therapy for psychosis into six different stages.

- Stage one is concerned with engagement with therapy. The assessment interview is conducted to identify the individual's current difficulties, and to look for predisposing and maintaining factors.
- Stage two involves advice and education concerning a wide variety of coping strategies to assist people to manage the positive symptoms of psychosis.
- Stage three includes offering alternative perspectives about the individual's experiences. Discussion is encouraged concerning the extent to which these perspectives can account for the individual's experiences.
- Stage four focuses on specific delusional beliefs or beliefs about hallucinations. The therapist may offer a reality based explanations or may work within the individual's existing belief system to promote more adaptive explanations.
- Stage five draws on the cognitive approach to depression and is concerned with identifying and challenging dysfunctional thoughts about the self and others.
- Stage six aims to consolidate the new perspective on the individual's difficulties and emphasising the importance of self-regulation of psychotic disorder, with reference to relapse management and social disability.

However, as the needs and idiosyncratic beliefs of each individual diagnosed with psychosis will be different, therapy is individually designed to address their particular difficulties.

Several authors discuss the limitations of the cognitive therapy approach. For example, Perkins and Repper (1996) argue that there is an inherent danger in challenging an individual's delusional ideas. They argue that as a delusion by definition is a fixed belief, there is little point in challenging it. They point out that individual's will have their
beliefs challenged in many different circumstances, by many different individuals, but will still hold onto the delusional belief (Perkins and Repper, 1996). Furthermore, they assert that challenging beliefs may prevent or detract from the development of a therapeutic relationship. They emphasise the importance of acknowledging that the experiences are real for the person concerned and for the therapist to respond to the emotional content rather than the factual content of the belief.

Romme and Escher (1989) argue against the medicalisation of the phenomenon of hearing voices. They assert that many people hear voices and cope with the experience well. They also suggest that the person's experience of hearing voices should be accepted and that therapy should aim to assist the individual to communicate with the voices, or to learn to distinguish between "good" and "bad" voices, instead of being focused towards challenging beliefs. However, they provide no evidence for these methods in helping people with the experience of hearing voices.

**Outcome research**

One of the first controlled outcome studies of cognitive behaviour therapy for psychosis was conducted by Tarrier, Beckett, Harwood, Baker, Yusupoff and Ugarteburu (1993). They allocated 27 people to two forms of cognitive behavioural therapies; coping strategy enhancement and problem solving. Coping strategy enhancement (CSE) was developed in response to research (Tarrier, 1987) indicating people who used multiple coping strategies were more likely to report that their ways of coping were effective. CSE attempts to identify coping strategies that the client may already use and to build upon the strategies by demonstrating additional ones (cognitive, behavioural and strategies which produce physiological change). Potential stressors or triggers for positive symptoms are identified. CSE aims to “decrease symptoms by training the client to cope with and both control the cues and reactions to symptoms” (Tarrier et al, 1993).

Problem solving was selected as a control condition as it is an established treatment that
may result in benefits to the client but would not be expected to directly address positive symptoms. Therefore it was hypothesised that CSE would lead to a decrease in positive symptoms and that problem solving would increase functioning but would not have any direct action on positive symptoms.

Ten sessions of treatment were delivered over a five week period, with an initial assessment period to obtain a baseline measure. Both groups showed significant improvements compared to the waiting list group, which was maintained at six months. Delusions and anxiety improved, however hallucinations, depression and wider areas of functioning did not.

There was evidence that CSE was more efficacious than problem solving, with the CSE group showing greater improvement on the delusions scale. Furthermore, 60% of people in the CSE group demonstrated a “clinically significant” improvement (that is that they demonstrated 50% improvement in their symptoms) compared to only 25% who received the problem solving intervention. This suggests that CSE may be a useful component of cognitive behavioural therapy.

A high refusal and drop out rate, which the authors assert “is typical with this patient group” is reported. Of the 48 people who were considered suitable for the study only 27 (56%) continued to post treatment and 23 (48%) to six month follow-up. If this finding is consistent with other cognitive behavioural interventions for psychosis, this would obviously limit the usefulness of this approach. Furthermore, caution must be exercised when interpreting the results of the study. First, relatively few people were included in the trial (n=27). Second, the assessors were not blind to which treatment the client was receiving which may lead to bias in the ratings.

Drury, Birchwood, Cochrane and Macmillan (1996) report the results of a controlled trial of cognitive therapy with 40 people in the acute phase of a psychotic disorder. The
sample was randomly allocated to two conditions; one group received both individual and group cognitive therapy whereas the other received the same amount of therapist input, but the time was spent in structured activities combined with informal support. Medication was prescribed by consultant psychiatrists who were blind to the two conditions and not part of the research team. Self report scales and mental state assessments were conducted weekly to monitor change.

As noted earlier, the cognitive therapy provided in the study consisted of both individual and group intervention. The individual therapy focused on the challenging and testing of key beliefs. Group therapy aimed to allow individuals to notice how others’ beliefs often were inconsistent and irrational, and alternative explanations for these beliefs were considered. New coping strategies for positive symptoms were developed and people were encouraged to “face up to and integrate their illness rather than seek refuge in psychotic experience” (Drury et al, 1996). In addition, two sessions of family intervention was provided with the goal of instructing family members how to support their relatives’ attempts at managing their symptoms. Furthermore, a structured activity programme aimed at improving interpersonal and self care skills was held. The control group spent approximately eight hours in a structured activity programme, designed to raise activity levels and to provide informal support.

Overall, the people in the cognitive therapy group showed marked improvement in symptoms, functioning, and speed of recovery when compared to the control group. Their stay in hospital was significantly shorter (a mean of 54 days compared with 119 days for the control group). People who had received cognitive therapy also showed a significantly faster decay in positive symptoms and a reduction in the conviction with which they were held. They were also found to be less preoccupied with their delusional beliefs.
Although the results of this study appear very impressive, again caution must be exercised when interpreting the results. First, as with the Tarrier et al (1993) study, the raters who completed the weekly assessments were not blind to the treatment condition. Therefore there is a possibility of bias despite the researchers' intentions to be fair.

Second, the control condition consisted of an eight hour weekly activity programme designed to raise activity levels. It has been noted that the treatment of schizophrenia requires a low stimulation environment (Johnson, 1996). It is possible that the stimulation that the control group received may have slowed down their progress, thus giving the cognitive therapy group an advantage.

Third, the addition of family interventions to the cognitive therapy group means that it is difficult to conclude that the improvements were due to the cognitive therapy, as family interventions are known to be of demonstrable benefit to patients (Roth and Fonagy, 1996).

Kuipers, Garety, Fowler, Dunn, Bebbington, Freeman and Hadley (1997) report the largest randomised controlled trial of cognitive behavioural therapy for psychosis. Sixty participants were randomly allocated between a cognitive behavioural and standard care condition (control). The standard care consisted of the combination of pharmacological treatment and case management. Cognitive behavioural therapy was provided over a period on nine months to those with “persistent, enduring symptoms of psychosis” (Kuipers et al, 1997). One of the aims of the project was to engage as many participants in therapy as possible. Failure to engage in therapy, as evident in the high refusal and drop out rates reported by Tarrier et al (1993) is noted to be a difficulty with this client group. The initial sessions of cognitive therapy were therefore spent concentrating on engagement with therapy.
Assessments were administered at baseline, three months, six months and at the end of treatment. Follow up assessments at eighteen months had not been completed, therefore the data reported is concerned with the treatment phase alone. The cognitive behavioural therapy in the study was individually tailored but consisted of one or more of the following strategies:

- Improving coping strategies / developing and practising new ones
- Modifying delusional beliefs and beliefs about hallucinations
- Modifying dysfunctional schema
- Management of social disability and relapse - including relapse signatures (Birchwood, 1996).

Over the nine months, improvement was significant only in the treatment group, who showed a 25% reduction on a scale measuring overall mental state. Clinical change was determined by calculating the average variance of the control group on the measure of mental state over time. If an individual's improvement exceeded the average variance found in the control group, this was deemed to be clinically significant. Therefore, 21% of the treatment group achieved a large clinical improvement, and a further 29% of the achieved a "reliable" clinical improvement (Kuipers et al, 1997).

This means that approximately 60% of the treatment group showed greater improvements than the average improvement found in the control group, and that 40% of those in the treatment group did not show this improvement. Furthermore, there no change in levels of depression or measures of social functioning was detected. It can be concluded that in this study, CBT produced improvements in 60% of people, over and above standard care, but did not produce any overall reductions in depression or produce any change in social functioning.

Medication levels were examined at the start of the study and no differences were found between the two groups. However, over the nine months of the trial more control participants had their medication increased, whereas two of the treatment group had their
medication decreased. This meant that as the trial progressed more of the control group moved into the high medication category.

The reported drop out rates were low (18%) and those receiving the cognitive therapy completed a satisfaction with therapy questionnaire. 80% were satisfied or very satisfied with therapy. Only one person reported that ‘things had got worse’ and this person was also dissatisfied with treatment.

Kuipers et al (1997) conclude that cognitive therapy has the advantages that it has no unpleasant physical side effects, and can produce clinically significant change. However, the disadvantages include the amount of therapist time that is needed to produce the change, and the extra training and supervision that is required to support therapists.

Again, there are issues of concern with the design of the study which limits the conclusions that can be drawn. Once again, the assessors were not blind to the two treatment conditions and the possibility of bias must be considered. Second, the authors point out that as medication was prescribed by consultants not involved in the trial, it was not possible to keep all of the participants stable on the same medication. Therefore it is possible that some improvement may be due to increases or changes in medication. Third, as data from the follow up period has not been reported, it is possible that the improvements noted at the end of treatment may be short-lived.

Conclusions
The research to date into the application of cognitive therapy to psychosis is encouraging. Improvements in positive symptoms have been noted in all studies. However, although the studies have reported successful outcomes for positive symptoms, no change has been shown in social functioning in any of the reported studies to date. One study found that the levels of anxiety reduced after cognitive therapy, but it is a common finding that levels of depression remain constant.
As research in its infancy, there is currently no information concerning the relapse rates of those individuals who have been offered cognitive therapies. The high risk of relapse is an important issue in the treatment of psychosis, an issue that cognitive therapy claims to address, the lack of information means that its role in relapse management cannot be adequately assessed.

An area that the published studies fail to address is the therapist’s contribution to the effectiveness of cognitive therapy. Roth and Fonagy (1996) conclude that experience is an important predictor of outcome with people who are more severely disturbed. Only one study (Kuipers et al, 1997) states that the therapists providing the treatment were experienced, but gives no details concerning their experience or training.

Further research is necessary to investigate the efficacy of cognitive therapy for psychosis due to the small number of published studies and the methodological flaws that exist in those published. Research in which the raters remain blind to the treatment condition of the individuals is particularly important to avoid the possibility of bias. Furthermore, longitudinal studies would provide information about relapse rates and the duration of improvements in symptoms.

References


"Discuss the relevance of genetic anomalies to day-to-day clinical psychology work with people with learning disabilities."

People with Learning Disabilities Essay
June 1998
Year I
Introduction

In order to evaluate the relevance of genetic etiology to the work of clinical psychologists, two distinct perspectives will be outlined and discussed, views in support of etiology and views which recommend caution.

The argument will be made for considering genetic etiology when devising a psychological formulation and intervention plan, whilst being mindful of issues and assumptions that are often made about genetic anomalies. Genetic anomalies and the implications for clinical psychology will be examined in detail, using William's syndrome as an illustration. The importance of working with individuals specific needs and strengths will be highlighted. In essence, a synthesis of the two approaches will be argued for.

The term genetic anomalies has been taken to include both genetic errors and chromosomal anomalies (abnormalities of chromosome structure, abnormalities in the number of chromosomes and fragile sites).

Genetic anomalies and learning disability

There are a range of genetic anomalies which can be associated with learning disabilities (Clements, 1987). In 1933 Lewis (cited by Scott, 1994) made a distinction between individuals with identifiable syndromes, those who suffered birth or early life traumas, and those individuals who were "naturally at the lower end of normal genetic variation". However, for a large number of people with learning disabilities, etiology is still unknown (Goodman, 1990).

Recent developments in genetic science has lead to the identification of specific genetic anomalies and improved genetic techniques mean that "more people with learning disabilities can expect an etiologic diagnosis" (Berney, 1997). The debate concerning the utility of such a diagnosis will be examined.
As clinical psychology interventions are often concerned with the assessment of behaviour, the behavioural phenotype is of relevance. A behavioural phenotype “consists of a distinctive behaviour that occurs in almost every case of a genetic or chromosomal disorder, and rarely (if at all) in any other disorder” (Flint & Yule, 1994). This behaviour has a specific relationship to the chromosomal or genetic anomaly that gives rise to the physical manifestation of the syndrome. An example of this is the Lesch Nyhan syndrome (an X linked recessive condition), where compulsive self-injurious behaviour, verbal and physical aggression form the behavioural phenotype (Deb, 1998).

The historical context - “two cultures”

Hodapp and Dykens (1994) write of two “cultures” within learning disability research. They conclude that these “cultures” either classify individuals according to severity of disability or by etiology of learning disability. Moreover, they contend that clinicians and researchers utilising etiology often lack experience and sophistication in behavioural measurement and are often oblivious of current issues within the learning disabilities field. Conversely, those focusing upon level of impairment often remain unaware of the advances that have occurred in the genetics field. Therefore they argue for the importance of considering both genetic factors and severity of learning disabilities in both research and clinical practice.

In conclusion to a research review, they argue that each of the cultures are backed by separate professional groups, with geneticists and psychiatrists focusing on etiology and psychologists and educators focusing on the level of severity. However, this distinction is oversimplified, as clinical psychologists publish research examining psychological implications of specific genetic syndromes (e.g. Howlin, Davies and Udwin’s work on cognitive functioning in William’s Syndrome, 1998). It does account for a reluctance to consider the possible psychological implications of biological factors amongst clinical psychologists (Clements, 1987).
Problems with genetic etiology
It has been asserted that utilising genetic aetiologies can have adverse effects upon people who have learning disabilities (Goodman, 1990, Clements, 1987). Such adverse effects will be discussed.

Goodman (1990) in a critique of Burack, Hodapp & Zigler (1988), acknowledges that classification of learning disability according to etiology can be medically useful, but there is no such utility in social or educational contexts. She asserts that it is often unhelpful and may be detrimental to consider etiology the foundation of a diagnostic system. If the aim of diagnosis is to provide a prediction of future functioning and possible interventions, Goodman argues that descriptive indicators, based in intellectual functioning would be more useful. She asserts that an IQ level in combination with the individual’s chronological age can provide information about level of instruction, social expectations and likely rate of progress. An etiologic diagnosis gives no such information.

The application of a genetic diagnosis may give rise to a stigmatising label (Goodman, 1990). Clements (1987), writing about biological issues, highlights the debate that has occurred during the last few decades. It has been argued that by focusing on genetic etiology, the differences between learning disabled and non-learning disabled individuals are emphasised, instead of focusing on common human needs. This may have contributed to the medicalising of learning disabilities, portraying people as being “sick”. In contrast, the diagnosis of physical illness typically leads to selection of appropriate treatment, whereas a diagnosis of organic involvement has no such positive association (Clements, 1987). Current genetic research has lead to the identification of genetic anomalies, but has not lead to any interventions that can address theses anomalies. This perpetuates the idea of incurability, leading to assumptions that there may be little point addressing behavioural consequences associated with the syndrome, and that phenotypes are static and unchangeable.
In cases where there is a clear genetic etiology, there is always a complex interaction between genetics, social, psychological and biological factors. Simonoff, McGuffin & Gottesman (1994) assert that phenotypes are always affected by environmental factors and that the behavioural phenotype is the result of both the genes and the environment working together. An example of this is phenylketonuria (PKU) which is an autosomal recessive disorder (Berney, 1997) where treatment consists of dietary control to avoid phenylalanine. Those individuals who had received dietary interventions will be very different to those individuals who have not received the intervention, and the behavioural phenotype associated (irritability, anxiety, social isolation and reduction in concentration span (Berney, 1997)) with the condition may not be displayed.

Goodman (1990) asserts the relationship between cause and outcome is often oversimplified, as the same etiology can have a range of manifestations. Even though an individual may have a genetic etiology, the behavioural phenotype does not occur in all individuals. Berney (1997) argues that once an organic etiology is detected this can impede further assessment due to assumptions that every person with that syndrome will display the syndrome phenotype. In reality, only a minority of people will demonstrate all of the phenotype features in their full intensity with most cases demonstrating “fragments” of the phenotype, if indeed it surfaces at all (Berney, 1997).

All of the above problems with focusing on etiology has perhaps lead to the reluctance of many clinical psychologists to explore the psychological implications of genetic anomalies.

**In support of genetic etiology**

Clements (1988) writes “while fully acknowledging that organic concepts have often proved unhelpful to those who experience a degree of intellectual impairment, it would be foolish to deny the existence of the biological dimension in learning disabilities”. As a genetic dimension exists within learning disabilities, it is important to elucidate what it
involves and what implications it might have.

Present therapeutic techniques whilst preventing secondary handicaps cannot currently alleviate the genetic cause of the learning disability. It is important that genetic influences are researched fully in order to explore areas which could improve ways of helping those with learning disabilities. As information emerges concerning the relationships between genetic and psychological factors, this will help refine current psychological interventions and develop interventions incorporating both biological and psychological components (Hodapp, 1997).

Burack, Hodapp and Zigler (1990) argue that the cause of a person's learning disability is important and that the continued use of classificatory schemes based on the level of functioning will not enable advances in research or clinical interventions. They conclude in a review of research (1988) that there is evidence for the utility of differentiating retarded persons by etiology due to the behavioural differences between organically retarded groups. Therefore, this differentiation also has clear implications for intervention.

An organic diagnosis can be considered beneficial for the individual as it can enable proactive interventions to be implemented. Through knowledge of the behavioural characteristics which may accompany the syndrome, proactive interventions can be implemented instead of waiting until crisis point. An example of this can be seen with the Fragile X syndrome. Hagerman and Sobesky (1989, cited in Turk, 1992), report a cognitive behavioural intervention for female carriers of the Fragile X syndrome. The intervention aimed to reduce the emotional and social difficulties often experienced by carriers. The intervention included relaxation utilising biofeedback, developing social and practical skills, self monitoring procedures to slow thinking and grief counselling to work through the loss of the ideal self and associated guilt at harbouring a genetic defect (Turk, 1992). Other proactive interventions have been devised to deal with the associated
behavioural characteristics of the syndrome. It has been found that many individuals become more aggressive in adolescence (Turk, Hagerman, Barnicoot and McEvoy, 1994). Environmental evaluation and functional analysis of challenging behaviour should be conducted to establish factors which may be triggering and maintaining the aggression. Turk et al (1994) report that the aggression is often caused by sensory over stimulation, and research has demonstrated that counselling can assist the individual to communicate their frustration and enable the learning of coping strategies (Brown, Braden and Sobesky, 1991). The recognition that aggression may be a result of over stimulation should lead to the implementation of appropriate interventions.

Although it is often assumed that a behavioural phenotype is static and unchangeable, there is evidence to suggest that it can be modified and altered. Bull and Levecchio (1978), cited in Clements (1987), report on an individual with Lesch Nyhan syndrome, where self injury is part of the behavioural phenotype. Using a combination of desensitisation to the removal of restraints, ignoring and time out procedures, self injurious behaviour was managed successfully (Clements, 1987).

The recognition of genetic syndromes and their behavioural phenotypes has been beneficial for parents and carers. Flint & Yule (1994) assert that this recognition has been responsible for the change in attributions of parental blame. In the past characteristics of specific syndromes have been thought to be due to parenting failures. An example of this can be seen in the Cornelia de lange syndrome where children reject physical touch, and with autism where individual’s typically have difficulties with reciprocal interactions and the ability to form relationships (Lord & Rutter, 1994), both of which have been attributed to a failure of parenting (Flint & Yule, 1994). The recognition of the behavioural phenotype may alleviate the carer’s sense of guilt and responsibility, and isolation can be reduced by providing networks of individuals who have similar experiences through the carers group forum (Berney, 1997).
It is been found that individuals with a common etiology have a common neurodevelopmental trajectory. For example, people with Down syndrome show heightened visual processing and particular and possible etiologic specific difficulties with language (Burack et al, 1990) whilst individuals with Fragile X syndrome have common weakness in sequential processing. This is important when intervening therapeutically, as individuals with Down syndrome are more likely to respond to signs and symbols, whereas such interventions would not be as successful with individuals who have Fragile X, who would respond to “gestalt” interventions (Hodapp, 1997).

For some individuals with an organic etiology, there are often “critical consequences for the degree of handicap as they grow older “ (Scott, 1994). For example, there is a link between Down syndrome and dementia of the Alzheimer’s type. Bauer and Shea (1986) state that among persons with Down syndrome over the age of 35 the “neurological changes of Alzheimer’s disease have been consistently documented”. The knowledge of the link between Alzheimer’s disease and Down syndrome enables early signs of dementia to be detected, and appropriate interventions and services to be planned. However, this link could cause misdiagnosis of behavioural changes that occur as a response to environmental changes or emotional trauma, as it may cause diagnostic overshadowing.

The implications of genetic anomalies is therefore of great relevance to clinical psychology, both in devising appropriate interventions and in exploring the psychological implications of behavioural phenotypes to increase further understanding, and possibly lead to new treatments which may address these implications.

William’s Syndrome - implications for clinical psychology
This is a disorder which is marked by increased intestinal absorption of calcium. It is usually identified early in life through the presence of a characteristic face and heart defects (Flint & Yule, 1994) or through failure to thrive and feeding difficulties
(Clements, 1988). Recent research indicates that it is a continuous gene deletion syndrome (Howlin, Davies & Udwin, 1998). Although the raised calcium levels are treatable by dietary intervention but this does not have much of an effect upon health or eliminate other problems associated with the syndrome (Clements, 1988).

The psychological aspects of William’s syndrome include difficulties in cognitive, linguistic and social skills. Individuals with the syndrome will have a degree of intellectual impairment and a developmental trajectory unlike those of children who have other causes of learning disability. This trajectory includes diminished visuospatial functions and problems with gross and fine motor skills. This is of importance to clinical psychology interventions. For example, difficulties with visuospatial and motor skills would mean that skills teaching interventions would have to specifically target these areas (Udwin, Yule & Martin, 1987). Furthermore, skills teaching would need to utilise the areas of strength such as spoken language rather than using visual material, which is one of the deficits associated with the syndrome.

The William’s syndrome behavioural phenotype includes the tendency to use more adult vocabulary and social phrases (Flint & Yule, 1994). Although speech is often sophisticated, there is typically a lack of comprehension (Clements, 1988). This gives the impression of ability which can misleadingly overshadow their difficulties in understanding.

Poor peer relationships are noted in William’s syndrome children accompanied by excessive friendliness to adults. Early psychological interventions could be focused on improving peer relationships, possibly reducing social isolation and preventing secondary handicaps.

Some behavioural difficulties that may be faced by individuals with the syndrome include eating and sleeping difficulties. With this knowledge, the importance of developing
sleeping patterns can be stressed and any difficulties can be detected early on.

Many individuals have a hypersensitivity to specific noises which manifests as a clear noise phobia. The hypersensitivity is expressed in an exaggerated startle response with a resultant high level of anticipatory anxiety and hyperactivity. Udwin, Yule and Martin (1987) describe a typical response of a child with the syndrome to noise such as vacuum cleaners, electric shavers and laughter of a certain pitch. On hearing these sounds the children put their hands over their ears and screamed, or attempted to avoid the source of the noise by either running away or attempting to stop the noise. Psychological interventions utilising desensitisation principles could be usefully employed at an early stage to alleviate the anxiety and distress often caused.

To conclude, knowledge about the behavioural phenotype associated with William’s syndrome will enable the clinical psychologist to formulate and carry out proactive interventions, aimed at improving the individual’s quality of life. Although the psychologist should be aware of the phenotype, it should be acknowledged that not all individuals with the syndrome will display all or any of the features of the behavioural phenotype.

Conclusions

The diagnosis of a syndrome carries the risk that the individual will be expected to conform to their stereotype, “living down to their label” (Berney, 1997). However, against this the help that can be given must be balanced (prognosis of disability, appropriate and proactive interventions). Although interventions should be ultimately be based on individual’s needs and profile, genetic research can clearly provide general guidelines that tailor intervention approaches (Hodapp & Dykens, 1994). The extent to which the individuals' difficulties are due to genetic anomalies must be considered, to avoid the problems of stereotyping. It is perhaps wiser to view causation as a multifactorial process, with genetics being one influence (but an important one) on an individual.
In conclusion, genetic etiology is one of a range of factors to be considered when working with people who have a learning disability, however, of prime importance must always be the individual's needs.

References


American Journal of Orthopsychiatry, 59, 142-152.
"Clinical depression is an adult phenomenon and has little relevance to children and adolescents. Discuss"

Year II

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Child, Adolescent and Family Essay
Introduction
The existence of clinical depression in childhood is a controversial issue (Harrington, 1992) that has been the subject of much research and debate over the past forty years. Historically, there has been a tendency to deny the existence of depression in children, e.g. psychoanalytic perspectives, whereas current perspectives on childhood depression acknowledge that the condition is real, and research is concerned with identifying its defining characteristics (Carlson and Garber, 1986). Epidemiological evidence has accumulated indicating that some children can be diagnosed with clinical depression, which appears to be akin to the kind of depression suffered by adults. However, it is also possible that many more children suffer from depression but the symptoms do not fit with that of the adult disorder, as developmental differences in the presentation of depression have not been fully examined.

In this essay, the early perspectives on childhood depression will be briefly examined with the focus of discussion on epidemiological research and its limitations. An argument will be made that depressive disorders exist in children, and although they may be illustrated by developmentally specific manifestations, the underlying disorder is nonetheless the same as found in adults. The theoretical models of depression will be briefly outlined and their relevance to children discussed.

Definition
It is important to be aware that there is a difference between normal feelings of depression, and an abnormal depressive illness (Rutter, 1986). Depression as a symptom refers to a sad affect (Kazdin, 1990) whereas as a syndrome refers to a larger cluster of symptoms that go together. Angold (1988) notes that the literature on childhood
depression has been "as confused as its adult counterpart". Carlson and Cantwell (1980) identified three uses of the term depression. First, the symptom of depression refers to a single element of low mood, possibly better regarded as depressed mood, rather than as depression (Angold, 1988). Second, a syndrome of depression consists of a reliable constellation of symptoms that occur together. The final concept consists of depressive disorders, which have common factors such as etiology and prognosis, as well as being assessed using formal psychiatric criteria.

Evidence for the experience of depression as a symptom was gathered by Bowlby (1969) and Robertson & Robertson (1971, cited in Rutter, 1986) on toddlers admitted to hospital or to a residential nursery. These observations illustrated that children experienced an affective response to separation from a caregiver (the protest-despair-detachment sequence). This response seemed to constitute an understandable response to the loss of a loved person. Although this sequence illustrates an affective response, it is not sufficient to fulfil the diagnostic criteria for depressive disorders (Garfinkel, 1994). The responses of toddlers to a short period of separation usually disappear quickly when the parent returns whereas depression as a disorder is typically a recurrent problem (Harrington, 1993).

It is the notion of depression as a syndrome or disorder in children that has been debatable. The identification of depression as a disorder in children relies on the adaptation of the adult criteria of depression, a point that will be returned to in the course of this essay. An example of such adapted criteria can be seen in DSM-IV. For a diagnosis of a major affective disorder to be made, five or more given symptoms must be present, and one symptom must include a depressed mood or loss of interest or pleasure.
(DSM-IV, APA, 1994, page 327). In children, a depressed mood can be modified to an "irritable mood", and weight loss may be evident in failure to meet expected weight gains.

**Early approaches to childhood depression**

*Psychoanalytic Approaches*

Freud viewed depression as the result of aggression turned inward, which in turn results from the loss of an ambivalently loved object (Rutter, 1986). Depression in adults was thought to be a consequence of interpersonal loss during early stages of development. According to this theory, children have not fully resolved the oedipal conflict which results in the superego, or conscience forming. This conflict is usually resolved during the adolescence period. As guilt, self blame, and remorse were among the central features associated with depression in adults, it was thought that depression could therefore not exist without a fully developed superego. An example of this argument is to be found in a paper by Mahler (1961):

"We know that systematised affective disorders are unknown in childhood. It has been conclusively established that the immature personality structures of the infant or older child is not capable of producing a state of depression such as that seen in the adult"

Newman and Garfinkel (1992) claim that the psychoanalytic arguments are based on circular reasoning. The observations of adults have led to the identification of symptoms of depression, children who use different (immature) defences do not conform to this model, and they therefore cannot be depressed. It is assumed that in order for depression to be present, children have to have passed a particular psychological milestone. The
authors assert, that if this reasoning were followed through, it would therefore mean that some individuals who have intellectual impairments could not become depressed. Furthermore, they cite research by Greenacre (1971), who found that many depressed adults also have not achieved object consistency or specific superego development.

In summary, the psychoanalytical position states that the full development of the superego is a prerequisite for depression, and because this does not develop until adolescence, children therefore cannot be depressed. Research evidence has accumulated which demonstrates that this theory is not accurate (e.g. some depressed adults have not achieved full object consistency).

**Masked depression**

The concept of masked depression, is the idea that depression in children presents in other ways, such as conduct disorder or somatic complaints, which completely mask the underlying depression. The symptoms of depression in children are expressed in behavioural equivalents rather than being directly observable (Carlson and Garber, 1986).

The concept of masked depression was first raised by Glaser (1967, cited by Vermilyea, Heimberg and Silverman, 1985) who asserted that depressed affect may not be a core feature of depression in children. Several symptoms were thought to be behavioural equivalents of an underlying depression, such as hyperactivity, aggressive behaviour and somatic complaints. Some of the clinical implications of this argument are that it would be extremely difficult to identify depression from other disorders if they present as separate conditions which may be treatable in their own right (Vermilyea, Heimberg and Silverman, 1985). This would mean that it would be impossible to select an appropriate
treatment as it would be difficult to identify whether to address hyperactivity for example, or the depression that is theoretically underlying it. The criteria for establishing the presence of depression and for differentiating between disorders that may mask depression from those that have no underlying depression have never been adequately outlined (Carlson and Garber, 1986).

This perspective has been challenged by Carlson and Cantwell, (1980) who studied 28 children who met diagnostic criteria for depression. As 14 of this sample of depressed children had a pre-existing psychiatric disorder, the symptoms of these coexisting disorders did not completely mask the symptoms of depression. Critics of this approach have maintained that disorders that have been characterised as "masking" depression include practically the "full range of possible psychopathological disorders of childhood" (Carlson and Garber, 1986).

Instead of the masked depression described, it may be more useful to conceptualise such presentations as evidence of co-morbid disorders, rather than one disorder overshadowing underlying depression.

**Epidemiology**

In order to establish the relevance of the concept of clinical depression in children, it is necessary to review the epidemiological research. In order for the concept to be relevant, the disorder should be identifiable in children and have clear implications for prognosis and treatment.
Methodological issues

Before examining this data, it is vital to identify some methodological issues that exist when researching this field. Most of the studies apply adult diagnostic criteria to assessing depression to children. This method of identifying depression focuses attention on those symptoms which may be similar and ignores possible developmental differences. The fact that depression as a syndrome can be identified in children, adolescents and adults does not mean that the presentation of the disorder are identical (Kazdin, 1990). Furthermore, Cichetti and Schneider-Rosen (1986) argue that children who satisfy the criteria for DSM-II may in fact have a disorder whose etiology differs from adult depression. These points will be examined in greater detail throughout this essay.

There are other methodological difficulties in identifying depression in children. Much investigation has concerned the development of techniques for assessing depression in children and self report scales have been predominant in these developments. Self report methods are vital, as symptoms of depression such as sadness, feelings of worthiness, and loss of interest in activities reflect subjective perceptions (Kazdin, 1990). Studies which use only self report scales which measure the extent of depressive symptoms, can not argue that children who score highly on such scales fit the criteria for a depressive disorder. Furthermore, measures of depression that gain information directly from children may be subject to methodological flaws. There are obvious difficulties assessing depression in young children because of their limited ability to describe their feelings and emotions (Rutter, 1986). The extent to which some young children are able to accurately report their feelings and cognitions is questionable. Moreover, some research has suggested that young children may be unwilling to report their depressive feelings, for
example as seen in reduced frequencies of reporting these symptoms when compared to those symptoms reported by parents. These differences in reporting may reflect different biases on part of children and their parents, for example the reluctance shown by some children may reflect a desire to protect their parents from distress.

Kazdin, Colbus and Rodgers (1986) asked children and their parents to complete standardised measures of depression. The results indicated that parent ratings of severity of depression were consistently higher than the child ratings. In the Newcastle Child Depression Study (Barrett, Berney, Bhave, Fumuyiwa, Fundidis, Kolvin and Tyrer, 1991) further evidence for lack of agreement between parent and child was presented, some features which are perhaps more subjective in nature were reported twice as often by the child as the parent (e.g. suicidal ideation). Kazdin (1990) concludes that children are likely to be better reporters of their internal feelings and cognitions, whereas parents are likely to be better observers of behavioural presentations. Therefore studies that investigate depression in young children should utilise both child and parent as a source of information, in order to minimise sources of bias.

Prevalence
There are large discrepancies in the prevalence of childhood depression found in studies to date. Angold (1988) suggests that these discrepancies in estimates of prevalence may be due to differences in definitions and measures used by the studies (e.g. differences found between self and parental reports and diagnostic criteria). This means it is difficult to establish prevalence rates of depression, as different studies use different measures and criteria to assess their sample.
An example of this can be seen in the study by Kaplan, Hong and Weinhold (1984, cited by Kazdin, 1990). They used self-report measures of depression with cut off criteria. Using this criteria, 9% of a sample of high school students showed levels of depression (7.3% moderate and 1.3% severe). Roberts, Lewinsohn and Seeley (1995) surveyed a sample (N = 1,710) of adolescents using structured diagnostic schedules (DSM-III-R criteria). Although nearly 30% of the sample had at least one symptom of DSM-III-R major depression only 2.6% received a diagnosis. Therefore, children identified as having levels of depressive symptomatology may not meet criteria for formal diagnosis of depression.

In a research review of childhood depression, Kazdin, (1990) concluded that in the community samples approximately 2% of children aged 7-12 years have been identified as depressed in randomly selected populations, whereas in clinical populations, estimates of those with depressive disorders lie between 10 and 20%. A more recent review, (Birmaher, Ryan, Williamson, Brent, Kaufman, Dahl, Perel and Nelson, 1996) concluded that community studies of children and adolescents have reported prevalence rates of depression in children between 0.4% - 2.5%, and 0.4% - 8.3% in adolescents.

Gender differences
The research on depression in adults has shown a sex difference, with depression being more prevalent in women than in men (Kazdin, 1990). In the Isle of Wight general population study (Rutter, Tizard & Whitmore (1970/1981), cited by Rutter, 1986) a simplified psychiatric classification was used to identify levels of depression. At the age of ten, only three cases of depression in the sample of 2,000 children were identified. At the age of 14-15, there were 9 cases of depression and 26 of mixed affective disorder.
The depressive disorders in adolescence were more frequent in girls than in boys (Rutter, 1986). Birmaher et al (1996), concluded that by adolescence the female to male ratio is 2:1, which is similar to the rate found in adults.

**Age differences**

Kashani, Ray and Carlson (1984) found that very young children attending a child development unit (between 1 and 6 years of age) had a much lower rate of major depressive disorder (1%) than children between 9 and 12 years (13%) (Kashani, Cantwell, Shekim & Reid, 1982). The prevalence of depression in children appears to increase with age and developmental level.

**Course**

One way to identify whether childhood depression is a similar phenomenon to depression in adults is to examine data from longitudinal studies (Kazdin, 1990). Lifetime prevalence rate of major depressive disorder in adolescents estimated to range from 15-20%, which is comparable with the rate of depression found in adult populations (Birmaher et al, 1996).

The course of depression has been monitored in a group of over 100, 8-13 year olds who were diagnosed with depression using DSM -II criteria (Kovacs & Gatsonis, 1994). The group were followed for several years to look at recovery from depression and the risk suffering a future depressive episode, or other mental health problems. The median time of recovery was 9.5 months. However, children with major depression showed a high cumulative probability of a further episode of major depression during the following 68 months. In a different study, (Kovacs, Akiskal, Gatsonis & Parrone, 1994) following a
group of children for an average of six years, it was found that 50% of children with affective illness had at least one further episode by the age of 17 years. Kovacs (1994) concluded that depressed children continue to have a high risk for later episodes of depression and impaired functioning.

Harrington, Rutter and Fombonne (1996) report data gathered at the Maudsley Hospital over nearly twenty years. 80 cases of childhood depression and 80 nondepressed child psychiatric cases were followed up. Participants were a mean age of 13 years at the time of their initial attendance and were re-examined at a mean of 31 years, with data available for 82% of this sample. They conclude that the childhood depression group had a much greater risk for a depressive disorder in adulthood than the controls. Moreover, no other psychiatric disorder was increased, indicating that this risk was specific to depression.

Birmaher (1996) concludes that long term studies have found that depression is a long term condition with a cumulative probability of recurrence of 40% by 2 years, and 70% by 5 years. Many children go on to experience depression in adulthood, as found by Harrington, Rutter and Fombonne (1996). The mean length of depressive episode was found to be 7 to 9 months, with 90% of depression remitting by 1.5 - 2 years time. Kazdin (1990) summarises that the findings parallel those obtained with adults which show the pattern of remitting and relapsing often found in adult depression, with high recovery rates for episodes of depression but an equally high risk of future relapse.

To summarise, the epidemiological data suggests that depression in childhood is relatively rare in early childhood, with an increase in depression over the course of childhood and with symptoms beginning to parallel adult depression during adolescence.
Treatment studies

If the concept of childhood depression as a disorder is to be of relevance, there should be clear implications for treatment. Target and Fonagy (1996) in a review of psychological treatment for child and adolescent psychiatric disorders, concluded that very few studies have evaluated psychological treatments for clinical depression in children. They report a study (Stark et al, 1987, cited in Target and Fonagy, 1996) evaluating a group intervention designed for 9-12 year olds, drawn from social learning theory and cognitive therapy. One group in the study received a therapy modelled on cognitive therapy approach used with adult populations, and the other received behavioural problem solving techniques. Children were treated in small groups with the intervention lasting for 12 sessions. The authors concluded that children in both groups showed significantly reduced depressive symptoms in comparison with a waiting list control, with gains maintained over an 8 week follow up period. However, Target and Fonagy (1996) argue that due to the large number of comparisons of related measures (with no adjustments) the possibility of Type I errors is greatly increased. They conclude that the adaptation of treatments for depression which have been developed for use with adult populations appears to be productive, the efficacy of these treatments have yet to be demonstrated with a child population.

In a more recent study (Vostanis, Feehan, Grattan and Bickerton, 1996), examined the efficacy of cognitive behaviourial therapy for children and adolescents with depression. The key components of their approach was self monitoring, social problem solving and
cognitive restructuring. The CBT intervention was compared with a non-focused control intervention. The results showed that both of the groups improved significantly on depression measures, with 87% of the CBT and 75% of the controls no longer meeting criteria for clinical depression. The high level of improvement found in both the CBT and the non-focused supportive intervention may indicate that it was elements other than the cognitive restructuring and problem solving that were the mechanism for change (e.g. being a group member, therapist empathy, being listened to) or that levels of depression improved due to the passing of time. Nonetheless, greater improvements were made by those children receiving the cognitive behavioural intervention. This is further evidence that depression in children responds to therapy in a similar way and therefore could be considered the same disorder as depression in adults.

In conclusion, it appears that treatments developed for use with adult populations have shown some reductions in depressive symptoms in children. The improvement after treatment lends further support to the concept of depression as a disorder in children. However, there have been few trials with depressed children and further research is necessary whether clinical improvement is related to specific therapeutic techniques (Vostanis et al 1996).

Models of depression

Four main models of depression have been suggested; reinforcement, cognitive, life stresses and genetic/biochemical factors (Garfinkel, 1994). Each model will be briefly summarised.
The behavioural reinforcement model (Lewinsohn and Hoberman, 1982, cited by Kashani and Sherman, 1988) suggests that depression arises from limited social reinforcement. Such limited reinforcement may include the insufficiency of positive reinforcement, fewer social skills that elicit less positive reinforcement, and aversive or punishing environments. Family factors such as cohesion and conflict are encompassed by this model (Garfinkel, 1994). Living with depressed parents has been associated with higher rates of depression in children (Weissman, Gammon, John, Merikangas, Warner, Prusoff & Sholomskas, 1987, cited by Harrington, Rutter and Fombonne, 1996), perhaps due to the children receiving less positive reinforcement. However, this model does not explain why these children fail to develop adequate social skills in the first instance, and not all children who live in these conditions become depressed (Garfinkel, 1994).

The cognitive model assumes that depression results from negative cognitions that the child has about themselves, the world and the future. Patterns of thinking lead to a selective and negative view of self, with inadequate self monitoring, self evaluation and self reinforcement (Garfinkel, 1994). Lewinsohn, Steinmetz, Larson and Franklin (1981) argue that after the remission of depression, these cognitive symptoms disappear and the individual returns to a more positive and optimistic cognitive style. Kashani and Sherman (1988) argue that it is not clear whether the cognitive styles observed in depressed adults and children reflect causes, consequences or co-effects of depression. This model does not adequately explain the existence of depression in younger children, who may not have developed the necessary cognitive processing systems (Rutter, 1986).

The life stress model proposed by Lefkowitz and Burton (1978) asserts that depression is the result of environmental stress and loss within the family, for example divorce or bereavement. They argue that depression is a transient manifestation of developmental
reactions to stress in normal children. This model has been criticised by Garfinkel (1994) who argues that environmental loss and stress cannot always be detected in families of depressed children, and that some children who experience such loss and stress do not become depressed.

The genetic / biomedical model proposes a genetic predisposition to depression. This genetic factor alters the neurochemical regulation of mood. Research indicates that for affective disorders the concordance rates for monozygous twins is approximately 76% whereas for dizygotic twins it is 19% (Garfinkel, 1994). Although this demonstrates that there is likely to be a genetic component, as the concordance rate for identical twins is not 100%, depression is unlikely to be entirely the result of a genetic etiology.

Many authors have argued for a common pathway for childhood depression with multiple determinants that include social, genetic, life events and environmental factors which all interact to create depression (e.g. Harrington, Rutter & Fombonne, 1996, Garfinkel, 1994).

**Depressive disorders in children**

Some theorists have argued that depression in children is isomorphic with that found in adults (e.g. Garfinkel, 1994), and that key core components of adult depression can be applied successfully in diagnosing children with major affective disorders. For example, Garfinkel (1994) asserts that affective disorders in prepubertal children are best conceptualised and defined according to a schema that includes the diagnostic criteria applied to adults. Furthermore, he argues that because children and adolescents do not accurately verbalise their affective states, depressive symptoms are harder to recognise.
but still exist in the same form as observed in adults.

The opinion that depression in children manifests itself in the same way as in adults has led to the acceptance and use of DSM IV (APA, 1994) criteria as a basis for diagnosing major affective disorder in children, as previously discussed. DSM- IV outlines a number of symptoms that constitute major depressive disorders in children, adolescents and in adults. The criteria allows for limited variation in presentation according to the age and development of the client (e.g., substitution of irritable mood for depressed mood).

Research supporting this view, was conducted by Carlson and Kashani (1988) who examined the frequency of depressive symptoms in four psychiatric referred populations, preschool and pubertal children, adolescents and adults. Symptoms such as depressed mood, diminished concentration, sleep disturbance and suicidal ideation occurred with similar frequencies across the samples. Symptoms such as anhedonia, diurnal variation, hopelessness, psychomotor retardation and delusion increased with age (Carlson and Kashani, 1988). Indicators such as depressed appearance, low self-esteem and somatic complaints lessened with age. When compared with adults, children and adolescents diagnosed with depression have higher rates of anxiety, somatic, aggressive and irritability symptoms. The conclusion the authors draw are that age modifies symptom frequency but does not alter the basic phenomenology. This conclusion is questionable as other studies have indicated that depression is characterised by different presentations in different age groups. For example, Borchardt and Meller (1996) studied 22 pre-adolescents and 34 adolescent inpatients, diagnosed with major depression according to DSM-III-R criteria. They found that the variables associated with adolescent presentations included melancholia and suicidal attempts, whereas those symptoms which
characterised pre-pubertal age group were temper tantrums, distractibility and irritability. Temper tantrums are not part of the diagnostic criteria for depression, but nonetheless were found to be associated with depression in younger children. This suggests, that in contrast to the view above, there may be different age specific manifestations of depression.

Furthermore, research supporting this perspective is based on adult criteria for depression. As the authors only considered depression to exist if it met the adult criteria, they were obviously going to identify depressive disorders that mirrored those found in adults. Very few children are identified as experiencing a depressive disorder when using this diagnostic criteria. The use of a modified classification system would allow for further examination of depression in children, perhaps identifying children who would benefit from treatment of depression but would be excluded under the above criteria.

A more helpful way of looking at the concept of depression in children is obtained by adopting a developmental perspective. Developmental perspectives on mental health problems are concerned with the process of development through childhood, with an interest in continuities and discontinuities of development (Rutter, 1986). The focus is on age and developmentally related isomorphs, continuities and discontinuities between one developmental period and the next, and transitions between them. It is therefore unrealistic to expect behavioural isomorphism in depression (Rutter, 1986). For example, the protest-despair-detachment response exhibited by toddlers upon separation from caregivers can be considered a normal response during this developmental period, but may be considered abnormal as the child becomes older. Important differences in developmental progression will produce differences in interpretation, experience, and
expression of depressive symptomatology over time (Carlson and Garber, 1986). Therefore, appropriate diagnostic criteria must incorporate age specific manifestations of the symptomatology.

Development and maturational differences influence the child’s ability to express affect, cognitions and behaviours, and thus the manner in which the symptoms are expressed may differ over the course of development. The adult based diagnostic criteria are not developmentally orientated as they fail to take into account possible age related differences in defining attributes or manifest expressions of the syndrome (Kovacs, 1986). Lefkowitz and Burton (1978) discuss the importance of placing clinical diagnoses of depression in a context of the incidence of behaviour in a normal population. Moreover, Cicchetti and Schneider-Rosen (1986) maintain that it is futile to try and define symptom characteristics that comprise the diagnostic picture for depression, without looking at the different manifestations at different ages and developmental level. They discuss the example of a child who suffers from depression between the pre-operational and concrete operational stages of development (Piaget, 1963 cited by Rutter, 1986). The manifestation of symptoms such as guilt, loss of self esteem and decrease in activity may change and develop during the transition, when the child’s cognitive, affective and behavioural competencies are changed radically.

Furthermore, developmental changes in children’s attributional capabilities may also play a part in the rise of the rate of depression during adolescence (Rholes, Blackwell, Jordan and Walters, 1980, cited by Rutter 1986). Younger children may have fewer feelings of helplessness because they do not view failure as indicating a stable and lasting limitation on their performance. Although, during the preschool years a child becomes aware of
standards and may experience distress if they fail to meet them, the cognitive processing required for symptoms such as a feeling of hopelessness are thought to be a much later cognitive development (Rutter, 1986).

Conclusions

The idea that children do not suffer from depression as a disorder is not supported by the research literature. Depressive disorders have been identified in numerous research studies, however the estimates of prevalence are wide, depending on criteria used in the research. Numerous parallels with clinical depression found in adults have been identified. Child and adult depression both often follow a cyclical, relapse - remitting, pattern. There appears to be a similar sex ratio apparent during adolescence, and cognitive behavioural treatments used with adults have been demonstrated to be effective in children. This supports the view that child and adolescent depression is the same phenomenon.

However, it is impossible for the same disorder to present in exactly the same way in both adults and children. Depression in children appears to be marked by different age specific manifestations, and the adult criteria used in the both research and clinical settings does not allow for these developmental presentations and may therefore not identify all those children suffering from depression. The research to date has only identified those children whose depressive disorder corresponds to the modified adult criteria. Given that research exists highlighting differing presentations at different developmental stages, the criteria for identification should be widened to ensure that all children receive the most appropriate treatment.
References


"Critically evaluate the effectiveness of psychological interventions for asthma."

Year II
July 1999
Specialist Essay
Introduction

Asthma is a complex disease which has considerable consequences for the individual. It can cause substantial physical disability, psychological distress and social isolation through the avoidance of activities that might bring on an asthma attack. The mortality rate for asthma is approaching 2,000 deaths per year in England and Wales (Lane, 1996a).

A definition of the disorder will be presented, highlighting the difficulties in identifying and researching the disorder. Causes of asthma will be outlined, focussing on the role of psychological factors.

Psychological interventions for asthma will be described and evaluated, with reference to outcome measures. Furthermore, gaps in psychological treatment developed for asthma will be highlighted, with discussion concerning possible applications to the disorder.

There is substantial literature concerning the management of childhood asthma, however the focus of this essay will be on psychological interventions for asthma in adults. The reason for considering only adult interventions and excluding studies examining children is twofold; first, the types of intervention conducted with children are different in type and delivery to that conducted with adults (e.g. a focus on family therapy and interventions with parents or carers). Second, Richter and Dahme (1982) argue that children under the age of 16 have 50-70% chance of becoming asymptomatic without intervention within 3-10 years. Remission of symptoms is well established, but relapse does occur for some individuals. Martin, McLennan, Landau, and Phelan (1980) and Kelly, Hudson, Phelan, Pain and Olinski (1987) followed up a group of children who had been diagnosed with at the age of seven. They re-interviewed this sample and assessed the prevalence rates of asthma at age 21 and 28. At age 21 a quarter of the sample were free of asthma, but by age 28, 30% of this group had relapsed.
Definition of asthma

No consensus has yet been reached on the precise definition of asthma (Woolcock and Peat, 1995), but a commonly used definition is by the American Thoracic Society (1987):

"Asthma is a clinical syndrome characterised by increased airways responsiveness of the tracheo-bronchial tree to a variety of symptoms... The major symptoms of asthma are paroxysms of dyspnoea (difficulty in breathing), wheezing, and cough, which may vary from mild and almost undetectable to severe and unremitting. The primary physiological manifestation of this hyper responsiveness is variable airways obstructions."

Asthma, chronic bronchitis and emphysema are regarded as chronic non-specific lung diseases. In practice, it is often hard to distinguish between these three disorders. In asthma periods of dyspnoea occur at irregular intervals and in between these episodes the person with asthma usually has normal pulmonary function. Episodes of airway narrowing are referred to as "acute attacks" if they are short lived and easily reversible, and "exacerbations" if they last longer than a day (Woolcock & Peat, 1995). Chronic bronchitis and emphysema usually are characterised by chronic breathlessness when resting as well as before and after exertion (Everaerd, Vromans and van der Elst, 1990).

It is thought that asthma is a response to the narrowing of the bronchial airways, caused by one or more of the following interconnected factors:

- mucus accumulating in the bronchial tubes
- the swelling of the airway lining
- bronchial muscle spasm

When asthma occurs, there is a narrowing of the muscles of the bronchial walls, which reduces the flow of air to the small air sacs. The contraction of the bronchial wall can cause interference in normal breathing. During an asthma attack, the membrane of the
bronchial tubes swell, causing an obstruction which impedes the flow of air. An excess of mucus is secreted which accumulates in the bronchial tubes, hardening as it dries thus further reducing the flow of air. The air becomes trapped in the lungs and the individual experiences shortness of breath, accompanied by a feeling of tightness in the chest, dyspnoea, a choking sensation and a coughing spasm which is an effort of the airways to remove the obstruction (Woolcock and Peat, 1995).

Incidence and prevalence

Lane (1996a) writes that "asthma is a clinical illness with an imprecise epidemiological definition". The incidence and prevalence of asthma are hard to measure, due to the lack of a generally accepted definition. The term can be confined to just wheezing or breathlessness, however other presentations such as coughs or chronic breathless may also be considered asthma.

According to the methods used to identify asthma, the epidemiological studies show considerable variation. For example, Woolcock, Peat, Salome, Yan, Anderson, Schoeffel, McCowage & Killalea (1987) examined the prevalence of one of the features of asthma, bronchial hyperreactivity. They found that although 11.4% of their population sample had bronchial hyperreactivity, only 5.9% of this group had other clinical signs of asthma. Therefore, an overestimation of asthma is likely if measures of bronchial hyperreactivity are used alone.

Woolcock and Peat (1995) point out that most measurement of asthma in populations has been made on the basis on questionnaire data. One method involves asking respondents to identify whether they have a diagnosis of asthma and for details concerning the severity of the disease. This method is subject to a number of biases; first, figures cannot be compared across cultures and communities as there is no standard criteria of asthma. Secondly, this method would not include individuals who have clinical symptoms but have not yet received a diagnosis. Other questionnaires attempt to address this issue by
asking about current symptoms of wheeze, but this is also problematic due to different cultural definitions of the term "wheeze" (Woolcock and Peat, 1995).

It is estimated that between 3-10% of the population of Great Britain suffer from asthma (Everaerd, Vromans and van der Elst, 1990, Newman-Taylor, 1995). There is a large difference in the prevalence of asthma across countries with the UK and Australia demonstrating higher rates than populations in the Asian Pacific region (Woolcock and Peat, 1995). Asthma in children has been shown to be increasing in all areas of the world where it has been measured. For example, in the USA, the prevalence rose from 6% to 12% between 1973 and 1988 (Burr, Butland, King and Vaughan, 1989), and in England and Wales there was approximately three times more children with asthma in 1992 than in 1982 (Rona, Chinn and Burney, 1995). Similar increases have been documented in New Zealand, Australia and Tahiti (Woolcock and Peat, 1995).

**Causes of asthma**

Lane (1996b) states that there are four possible interrelated causes of this contraction; irritable airways, allergens, infections / wheezy bronchitis and psychological factors. Each cause will be briefly outlined, focussing on psychological factors as this is of most relevance in addressing the question.

*Irritable airways (bronchial hyperreactivity)*

In asthma there appears to be an underlying irritability of the airways. The contraction of the bronchial muscles is a parasympathetic reflex; whereas the sympathetic system is responsible for dilating the bronchi. Airways appear to narrow in response to triggers such as the breathing of cold air, exercise, cigarette smoke, air pollution, changes in humidity and laughter. Brief episodes of wheezing are thought to be due exclusively to spasms of the bronchial muscle with little contribution from mucus or swelling (Lane, 1996b).
Allergens
An allergy is an unusual sensitivity to foreign objects such as atmospheric particles, food or industrial substances. In asthma the allergy is shown in the lungs by coughing and wheezing. This reaction causes difficulty in breathing. An allergic reaction may develop immediately on contact with the allergen (an atopic sensitivity) or after several hours (a late allergic reaction). It is estimated that about 10% of the population have severe atopy (Lane 1996b), and people who are atopic are likely to have asthma although it is not a precise correlation.

Infection & wheezy bronchitis
A common trigger for asthma appears to be infection of the breathing organs due to a virus or bacteria (bronchitis). Bronchitis and wheezing are often concurrently observed in people with asthma. Lane (1996b) asserts that in 80% of acute asthma attacks in children a viral infection causing wheezy bronchitis can be identified. It has been demonstrated that previously healthy people develop a degree of airway narrowing and irritability when suffering from a common cold (Lane 1996b). Viral infections attack the lining of the airways making them more sensitive and irritable.

Psychological factors
- Emotions
There is some evidence to suggest that thoughts and emotions could induce bronchial contraction. Luparello (1968, cited by Lane, 1996b) carried out research with forty people who had asthma, examining lung function. Measurements were made before and after inhalation of a neutral compound (dilute solution of salt). The participants were told that the substance was an allergen to which they knew that they were sensitive. In nearly half of the participants there was evidence of narrowing of the airways, and in a quarter there were obvious asthma attacks. Those people who suffered wheezing were then given a repeated dose of the same compound but were told that it was a treatment that would relax the airways, which resulted in improvements in wheezing for almost all of this sub-
group. This led to the conclusion that the suggestive information induced sufficiently intense emotions to result in bronchial obstruction in a proportion of people.

However, other authors have disrupted these findings and argued that the bronchial obstruction was not mediated by the emotive information, but by the inhalation of the neutral compound at room temperature. In order to examine this idea, Lewis, Lewis and Tattersfield (1984), replicated an earlier study but asked participants to inhale a neutral compound that was kept at body temperature. No bronchial obstruction occurred, although participants still reported difficulty breathing. This body of research indicates that emotions seem to affect perception of dyspnoea although there is inconclusive evidence as to whether emotional state can actually alter pulmonary function (Everaerd, Vromans and van der Elst, 1990).

- Panic / Anxiety

Smoller, Pollack, Otto, Rosenbaum and Kradin (1996) argue that panic anxiety is a frequent manifestation of pulmonary disease. Approximately 6-30% of people with asthma have been reported to meet the criteria for panic disorder, which is a higher than the predicted comorbidity of panic disorder with pulmonary disease (Smoller et al 1996).

It is difficult to identify whether anxiety and panic are a result or a causal factor of an acute episode of asthma. It has been argued that panic and hyperventilation may trigger episodes of asthma, perhaps by increasing airway exposure to cool, dry air (Smoller et al, 1996). Alternatively it has been suggested that pulmonary dysfunction with its associated symptoms could trigger catastrophic cognitions and panic in anxiety prone individuals (Ley, 1989). Furthermore, Smoller et al (1996) point out that common medications used in the treatment of asthma can be anxiogenic. Some authors have hypothesised that anxiety may be both a causal and mediating factor in the disorder (e.g. Smoller et al 1996), however there is insufficient research evidence to support this hypothesis.
In the long term, people with asthma may develop a cycle of excessive fear and avoidance of activities resulting in impairments in quality of life. Smoller et al (1996) argue that panic in people with asthma can lead to phobic avoidance of activity. Hyland (1998) points out that asthma affects the quality of life both when an individual is asymptomatic (most of the time) and symptomatic. The author asserts that there is a minority of people with moderately severe asthma who never have an asthma attack, but remain severely restricted by the prospect of such an attack.

- **Stress**
  The life stress model examines the link between environmental demands, psychological stress and health. Lazurus & Folkman (1987, cited by Ogden, 1996) place emphasis on the individual's active appraisal of a potential stressor and an evaluation of the individual's resources to cope with the stressor. Once an event has been evaluated as stressful, certain behavioural and psychological changes may be elicited (increases in fear, anxiety and anger, decreases in cognitive ability, Ogden, 1996). Biochemical changes relevant to asthma are also evident, for example the release of hormones and neuropeptides which are known to be responsible for the regulation of inflammatory and airway responses (Wright, Rodriguez and Cohen, 1998). Paradoxically, stress appears to activate the sympathetic nervous system which, as previously discussed, has the effect of relaxing the airways, whereas acute psychological stress (e.g. anxiety) activates parasympathetic responses including the contraction of the bronchi. Wright et al (1998) argue that the relative strength of the sympathetic versus the parasympathetic control in response to stress, differs from individual to individual, with some demonstrating a predominately parasympathetic response. It is these individuals who may be particularly vulnerable to stress induced contraction of the bronchi.

- **Brittle asthma and near fatal attacks**
  Two forms of brittle asthma are recognised which appear resistant to medical treatment. In type 1 there is a large diurnal variation in lung function for more than 50% of days
over the last five months, accompanied by persistent symptoms despite multiple drug
treatment, whereas type 2 is used to refer to asthma which becomes severe within
minutes (Harrison, 1998).

Miles, Garden and Tunnicliffe (1997) examined participants with type 1 asthma,
comparing them with asthmatic controls. Participants were compared using the General
Health Questionnaire - 60 (GHQ-60, Goldberg, 1986) and a score greater than 11 was
reported in 72.4% of those with brittle asthma, compared to 10.35 of asthmatic controls.
Furthermore, the GHQ -60 mean score was significantly higher in the brittle asthma
group.

Participants with type 2 asthma have not been subject to systematic research (Harrison
1998 ), however it has been observed that these people are often admitted with near fatal
attacks or die from their asthma (Sur, Crotty, Kephart, Hyma, Colby, Reed, Hunt &
Martin and Ruffin (1995) examined the link between psychiatric caseness, denial, and
self reported measures of handicap and morbidity due to asthma in a group of 77
consecutive hospital admissions for near fatal attack of asthma. 43% of the participants
scored in the caseness range of the GHQ-28. There was a positive correlation between
GHQ-28 score and limitation to daily activities due to asthma. The participants reported
high levels of denial, with 57% scoring more than 3 out of 5 on the denial scale of the
Illness Behaviour Questionnaire (Pilowski & Spence, (1994), cited by Campbell et al,
1995). Those with high denial scores were more likely to report presentation as sudden
collapse than progressive respiratory distress. They conclude that psychiatric caseness is
associated with high levels of morbidity in asthmatic patients who survive a near fatal
attack of asthma, and that high levels of denial in asthmatic subjects may be life
threatening.
Current research does not indicate whether the high levels of mental health problems which appear to accompany brittle asthma and near fatal attacks is a causal factor, or whether these problems are a result of having asthma that is very difficult to manage medically. There are obvious difficulties in establishing this without prospective evidence concerning mental health before the development of brittle asthma or a near fatal attack.

There is still debate concerning the relevance of psychological factors in the etiology of asthma. Steptoe (1984) argues that there is a complex interplay of psychological factors in both the etiology and maintenance of the disorder, whereas Kaptein (1997) asserts that there is no evidence that psychological factors cause asthma.

At the current time there is insufficient evidence to conclude that asthma can be caused by psychological factors, but there is convincing evidence that they may play a mediating role in the disorder, by shaping the response of the individual to the illness.

**Psychological interventions for asthma**

Respiratory medicines accounted for 11% of NHS prescribing in 1993, with almost two thirds of these prescriptions were for asthma. The cost to the NHS of asthma in 1993 was estimated to be £400 million, with most of this being spent on medications (Lane 1996a). In contrast to the vast literature concerning medical interventions for asthma, little has been written about the psychological treatment of asthma in adults.

Support for an association between psychological factors and asthma had its origins in the first part of the century. Early research suggesting a psychosomatic component to asthma was dominated by psychoanalytical theory that symptoms were a symbolic representation of unconscious intrapsychic conflicts and repressed desires (Wright, Rodriguez and Cohen, 1998). French and Alexander (1941, cited by Spittle and Spears, 1984) hypothesised that conflict concerned excessive unresolved dependence on the mother so that a threat of separation from her could precipitate an asthma attack.
Learning theorists argued that particular emotional experiences may have reinforced pulmonary physiological responses thus reinforcing the likelihood of occurrence (Everaerd et al, 1990). Current approaches emphasise the complex interplay of biological, psychological and social factors in the maintenance of the disorder (e.g. Rodriguez et al, 1998, Lane, 1996b).

Lehrer, Sargunaraj and Hochron (1992) categorise the various psychological interventions for childhood asthma into four approaches; psycho educational approaches to self management of asthma, stress management techniques, biofeedback methods directed toward self control of respiratory apparatus and family therapy approaches, examining the role of the family in mediating the disorder. Many of the same approaches have been used with adults, with the exception of family therapy, which has remained confined to work with children who have asthma. Each one of these areas will be discussed, outlining the elements of the approach and research concerning outcome.

*Psycho educational interventions*

Self management educational approaches have been the most common type of psychological intervention (Hyland, Ley, Fisher and Woodward, 1995) reported in the literature. These interventions have the primary aim of improving lung function, with physiological measures of peak expiratory flow and lung capacity and number of visits to casualty departments. It is hypothesised that improvements in lung function are obtained by encouraging adherence to preventative medication, avoidance of asthma triggers and encouraging the monitoring of peak expiratory flow so that the client understands when to increase medication (Hyland et al, 1995). It is thought that such programs encourage problem focused coping styles, characterised by seeking information and taking problem solving action (Lazarus & Folkman, 1984, cited by Hyland et al, 1995).

Gibson, Coughlan, Wilson, Hensley, Abraham, Bauman and Walters (1999) reviewed the literature examining the effectiveness of providing information to adults with asthma.
They concluded that the provision of information about asthma did not reduce hospitalisation, doctor consultations, affect lung function or medication use. However perceived asthma symptoms improved after the education. Clark and Nothwehr (1997) argue that many interventions rely heavily on the idea of transferring general asthma information to patients but the link between knowing a range of facts about a disease and changes in behaviour has not been established.

Clark and Nothwehr (1997) reviewed eighteen adult self management psycho educational interventions. They concluded that significant increases in asthma knowledge were found in six of the studies. Changes in participants perception of their disability were found in one study, another study reduced the level of "bother" due to asthma, and one study found less depression and participants reported increased confidence to manage the disorder. Reductions in the use of medication were reported in two trials, and two separate studies reported fewer doctor visits. Unfortunately, Clark and Nothwehr do not give details of how many trials included such measures in the evaluation, they only give details of the trials producing positive gains. It is therefore difficult to accurately conclude how beneficial the self-management interventions have been. Nonetheless, this review indicates the possible benefits that can be gained through psycho educational approaches to the self-management of asthma.

It is of interest that two trials showed that participants were more likely to adhere to the medical regimen. As other research has demonstrated that compliance with medication is negatively correlated with measures of psychological distress (Ford, Hunter, Hensely, Gillies, Carney, Smith, Bamford, Lenzer, Lister, Ravazdy and Steyn, 1989), the improved compliance may indicate improvements in psychological well-being.

Clark and Nothwehr (1997) conclude that asthma management behaviour is categorised according to attack prevention, attack management and social skills used to manage interpersonal relationships. The first two of these have generally been included in self
management interventions, whilst the third category is rarely addressed. They argue for more robust and effective interventions that address the client's social environment and the influence it exerts on their efforts to control the disorder.

In summary, research concerning self management approaches to asthma have shown improvements in a variety of domains. The variability in outcomes has been highlighted and further research is necessary to establish both the mechanism of change and the effective components of the interventions.

Stress / anxiety management approaches
These interventions are aimed at reducing anxiety and enabling people to learn more adaptive ways to cope with stress, based on the premise that conditioned stimuli, emotions and behaviour can cause or aggravate bronchial obstruction (Everaerd et al, 1990).

- Relaxation techniques
Relaxation techniques have been taught as an alternative way of responding. The effect of the treatment has typically been assessed by lung function and the number of asthma attacks. The aim of relaxation interventions is to improve lung function through the control of emotional triggers for asthma.

Richter and Dahme (1982) carried out a critical review of eight controlled studies of relaxation. Each study reported followed a fixed protocol and measurements were taken before and after treatment. Progressive muscle relaxation was used in each of the studies, but it was compared to systematic desensitisation in three studies. Six of the studies delivered the intervention on an individual basis whilst the other two provided group therapy. In total, 134 participants were included in the research. In seven of the studies the outcome of therapy was assessed by spirometry or peak flow meters (measures of lung function) and subjective symptoms were analysed in six of the studies (Everaerd et al, 1990).
One study showed deterioration in lung function, after reanalysis of the original data. No change in lung function was found in four of the studies and two studies showed an improvement. In the six studies that reported subjective measures of asthma symptoms, four studies found improvements.

Richter and Dahme (1982), conclude that in contrast to research involving children, there is no evidence for the effectiveness of relaxation therapy in the treatment of adult asthma. However, Everaerd et al (1990) point out that recording lung function is not a valid method for assessing the course of asthma, as lung functioning is typically normal between attacks. Periodic measurements tend to underestimate the severity of the disease by not including all episodes of bronchial obstruction (especially those occurring at night). Furthermore, some methods of assessing lung function (e.g. peak flow monitoring) require good technique, co-operation and motivation to obtain a valid and reliable measurement.

As there is evidence that emotional tension and parasympathetic activity produce bronchodilation, Everaerd et al (1990) conclude that relaxation treatment is only meaningful to the client when tension and emotions play an important role in their experience of asthma.

- Breathing retraining

Henry, de Rivera, Gonzalez-Martin, & Abreu (1993) compared a treatment and control group of asthmatic participants (N = 24) over an eight-month period. The experimental group was treated with autogenic breathing retraining aimed at reducing hyperventilation. The control group received supportive group psychotherapy. The volume of air which can be forced out of the lungs in one second was measured (FEV1 = forced expiratory volume in one second). The group who received the breathing retraining obtained a relevant clinical improvement (> 15% of pre-treatment values) in respiratory function. Furthermore, no significant changes were observed in the control
group. The authors conclude that these results show that autogenic breathing retraining could be an effective adjunctive treatment in bronchial asthma. However, the numbers of participants in the study was small, with just twelve individuals assigned to each treatment. Again, further research is necessary to confirm the effectiveness of such breathing training in reducing the number of episodes of asthma.

**Biofeedback**

Biofeedback techniques are employed to teach the client to reduce airway resistance. The aim of biofeedback is to help the client learn voluntary control of pulmonary function by providing feedback about physiological functions which they are generally unaware of (Steptoe, 1984).

There have been difficulties in selecting an appropriate measure of pulmonary function (Steptoe, Phillips and Harling, 1981). Peak expiratory flow and forced expiratory volumes assessed by spirometry are effort dependent measurements which, as previously mentioned, rely on the participant’s co-operation and motivation. Therefore, Steptoe et al (1981) argue, they are sensitive to the demand characteristics of clinical setting and may not be a valid and reliable measure of therapeutic intervention. In biofeedback, an unobtrusive, repeatable measure is a prerequisite of a feedback signal.

A very small number of studies have been carried out using a forced oscillation technique for recording total respiratory resistance. An example of such a study is by Steptoe et al (1981) who investigated the ability of participants (n=8) with asthma to exert voluntary control over pulmonary function. All participants underwent four training sessions and were provided with visual and auditory feedback for the duration of the session. The training was conducted under rest conditions. Four participants responded positively to the biofeedback trials, two showed no change and the remaining two participants produced increases in total respiratory resistance. The authors conclude that the results were encouraging, but biofeedback has not been demonstrated beyond short-term trials (Steptoe, 1984).
Future application of psychological interventions

Although the role of psychological factors in precipitating asthma is not widely agreed, there is currently evidence to suggest that psychological factors are important in mediating the effects of asthma. However, psychological intervention in the area of adult asthma appears to be confined to educational interventions and application of stress management techniques. There appear to be gaps concerning interventions aimed at both cognitive components of asthma related anxiety disorders and the impact of asthma on interpersonal relationships. Furthermore, given the association of mental health problems with near fatal attacks of asthma, it is surprising that few interventions focus on assessment and treatment of such problems.

Cognitive therapy

Cognitive therapy is based on the assumption that how one thinks has an impact on the way one feels and behaves. Emotional and behavioural responses are determined by the way an individual perceives, interprets and evaluates an event (Redlich and Prior, 1998). Underlying cognitive structures, referred to as schemas, are said to guide information processing. Schemas can act to create distortion and biases in automatic thinking that undermine functional cognitive processing. Therapy is a collaborative process of empirical investigation, reality testing, and problem solving.

Surveys of the psychological well being amongst people with asthma have shown that levels of anxiety and panic disorder are higher than those found in the general population (Carr, 1998). Some authors have therefore argued that the cognitive model of panic (Clark, 1986) could be usefully used with this population (e.g. Smoller et al 1996). Although much debated at a theoretical level, to date there is no study that the author is aware of that has examined the utility of this model as applied to adults with asthma.

Park, Sawyer, and Glaun (1996) examined the effect of a cognitive behavioural intervention in the treatment of childhood asthma complicated by high levels of anxiety.
The sample of children showed a marked discrepancy between objective measures of lung function and the child's experience of asthma. The cognitive behavioural intervention consisted of an educational component, cognitive restructuring, thought stopping and distraction techniques. The outcome measures included a reduction in hospital admission which was maintained at one year follow up. The outcome of this study is promising, however further research is necessary to compare cognitive interventions with general anxiety management techniques to assess which provide better improvements in anxiety levels (Redlich and Prior, 1998). A similar approach could be applied to adults with asthma complicated by high anxiety levels. Carr, Lehrer, Rausch and Hochron (1994) argue that such a cognitive approach could be used as a preventative intervention in adults with asthma, as they appear to have high risk of developing panic disorder.

Conclusions

Asthma is a complex disorder, but it is clear that the course of the disorder can be influenced by psychological factors. The research evidence to date suggests that breathing retraining can decrease airway resistance, psycho educational interventions can increase knowledge about asthma, compliance to medical treatment and reduce levels of depression and perceived levels of disability. The evidence concerning relaxation and biofeedback techniques is more mixed, with no clear evidence for efficacy.

Further applications of psychology to the treatment of asthma could be of benefit, particularly cognitive interventions for those people whose asthma is complicated by high levels of panic anxiety.

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"What is the potential for psychotherapeutic work with people with dementia?"

Year III

December 1999

Older Adults Essay
Introduction
This essay has several aims. First, the concept of dementia will be discussed and diagnostic criteria presented. Second, issues in the provision of psychotherapeutic approaches to individuals with dementia will be discussed. Third, the most widely utilised and researched psychotherapeutic approaches for people with dementia will be described and the evidence existing for each approach will be reviewed. In order to assess the potential for psychotherapeutic work with dementia the goals of psychotherapeutic work with this client group will be outlined and conclusions will be drawn based on the evidence to date.

Definition of dementia
Arendt and Jones (1992) write that dementia is not a disorder in its own right but a syndrome with a cluster of symptoms evident in many different combinations. The World Health Organisation definition of dementia is:

"the global impairment of higher cortical functions, including memory, the capacity to solve the problems of day-to-day living, the performance of learned perceptuo-motor skills, the correct use of social skills and control of emotional reactions, in the absence of gross 'clouding of consciousness'. The condition is often irreversible and progressive."

(WHO, 1986)

Dementia usually starts with slight impairments and progresses to a point where communication and self-care skills are lost (Arendt and Jones, 1992). Often the condition is divided into stages labelled mild, moderate or severe depending on the degree of impairment.

The syndrome of dementia can be produced by a variety of disorders. The most common form of dementia is Alzheimer's disease which is said to account for 40-55% of all cases, followed by vascular dementia. Some of the rarer forms of dementia are reversible and
these together account for 20% of cases (Arendt and Jones, 1992).

Kitwood and Bredin (1992) argue that although the neurological impairments of dementia set the boundaries of cognitive performance, there are other factors that shape the outcome of dementia. One factor includes the personality of the individual. Kitwood (1989, cited by Sixsmith, Stilwell and Copeland, 1993) suggests that some individuals have a psychological strength which allows them to remain intact as a social being despite significant cognitive impairments. The social care climate can be considered a factor that can influence the course of dementia. Kitwood (1993) argues that those with dementia are vulnerable to a "malignant social psychology" of the care environment that acts to deskill, devalue and dehumanise. As many care environments do not support the retained skills and abilities within the confines of neurological impairments, people withdraw and fail to function to the best of their abilities (Woods and Roth, 1996). Kitwood and Bredin (1992) argue that if an individual has individual care tailored to their own needs, a reverse process of "rementia" can occur in the areas of social skills and activities of daily living.

Epidemiology of dementia

Arendt and Jones (1992) review the epidemiological research and conclude that the incidence of dementia appears to be related to age with the prevalence of severe dementia being 0.1% between 30 and 60 years of age, 2-3% during the seventh decade and on average 17-50% in the ninth decade.

Woods (1995) asserts that the combination of the increase in the older population, especially those above 80 years of age, and the increase in prevalence of dementia with age means that there are a larger number of individuals suffering from dementia than ever before. Given this increase, therapeutic interventions for dementia are of great importance.
Psychotherapeutic approaches

Psychotherapy is a broad term that encompasses all forms of treatment that use psychological methods. There are many different types of psychotherapeutic approaches with each having different aims and utilising different techniques. Orrell and Woods (1996) ask the question of what constitutes a therapy in dementia. They speculate that approaches as diverse as environmental change, daily routine and modification of staff attitudes and interaction patterns, as well as regular sessions of intervention all qualify as psychological therapy. Bonder (1994) asserts that the common element of psychotherapy is a "mechanism for the expression and resolution of feelings". However, she also suggests that therapies may have a goal of enhancing existing intellectual abilities and increasing social interaction. Therefore, it is possible to consider most psychological interventions used in dementia as "psychotherapeutic" (including reality orientation, reminiscence therapy, resolution therapy, validation therapy and cognitive-behavioural interventions).

Before the research evidence concerning the efficacy of these interventions is discussed, issues in the provision of therapeutic approaches in dementia will be briefly considered.

Cheston (1998) reviewed the use of psychotherapeutic techniques with people with dementia. He asserts that the endings of therapy can be difficult and that as the disorder progresses the question of informed consent becomes a pressing issue. If therapy is delivered to people with dementia in their own home it may become difficult to know if the individual is consenting, as they cannot easily avoid the therapist visits. Furthermore, Cheston argues that an assessment of whether the work is still of value to the client must be made as the degree of dementia changes.

Hausman (1992) discusses several obstacles that arise when engaging in psychodynamic therapy with individuals who have dementia, one of these may be the family. The author suggests families are often unwilling for their relative to take part in any kind of therapy,
as they often view them as incapable of benefiting, with difficulties in remembering both sessions and everyday communication. This may lead to decisions being made about the usefulness of such sessions and subsequent poor attendance.

An assessment of suitability for the therapy should be made. Several authors have made claims about therapies being more suitable to individuals with specific patterns of impairment. For example, Terri and Gallagher-Thompson (1991) assert that cognitive therapy is more suitable for individuals in the early stages of dementia, and that behavioural strategies are more useful with clients with greater cognitive impairments. Jones (1995) argues that a consideration of the client's premorbid personality is essential and that criteria used to indicate success of psychotherapy in clients without dementia can also be used to indicate success in clients with dementia. Bonder (1994) asserts that individuals need to be assessed before group therapy to avoid including people who display disruptive behaviour and who therefore may be better suited to individual therapy.

Hausman (1992) discusses the issues of countertransference in work with older people. The therapist's own parent-child relationship may become a factor and feelings of anger, frustration and helplessness are often evident when working with individuals who have an illness that cannot be cured. The author asserts that these issues are more important when working with those who have dementia and questions of "will this happen to me?" often arise.

Clearly the presence of cognitive impairments must result in many adaptations to therapies themselves (Woods and Roth, 1996). Changes to the frequency and length of session have often been recommended. Terri and Gallagher-Thompson (1991) provided clients with a tape recording of each session. Bonder (1994) suggests that therapists should be more active than in other settings as clients may require much guidance and prompting.
Hausman (1992) argues that the function of thought, memory, speech and perception are often lost. Due to this, the client often uses inappropriate defences which may add to difficulties in engagement with therapy. The author suggests that splitting is often evident, where those around are seen in extreme terms, which may result in the alienation of those close to the client, possibly including the therapist.

Adaptations to the therapeutic context have also been suggested, with therapy occurring in a more informal context (Cheston, 1998), perhaps at an individual’s home environment rather than in the therapist’s office.

The psychotherapeutic approaches to dementia share many common values. Woods (1999) discusses the principles underlying the implementation of psychological approaches; that psychological and emotional needs are as important as the physical needs of an individual and that individuality is encouraged including dignity, self respect, independence and choice.

**Research issues in dementia**

Before examining the outcome of psychotherapeutic interventions, there are a number of research issues that apply with this client group. Firstly, as dementia can be a progressive deteriorating condition it is difficult to assess improvement when the baseline may be constantly changing. Furthermore, different disorders may give rise to different patterns of deterioration, with vascular dementia having a step-wise progression and Alzheimer’s disease showing a more gradual decline. A second issues concerns the physical health of the participants. Fluctuations in physical health may cause significant cognitive and behavioural changes that are not taken into consideration in most of the published research. A third point concerns what is considered to be a successful intervention. Kitwood (1995) argues that for some individuals personal growth occurs during the course of dementia. He collected retrospective information on 49 individuals thought to have experienced positive long-term change. The most frequent change was assessed to
be an increase in warmth and affection, followed by trustfulness, acceptance of limitations, assertion, spontaneity, overcoming depression and shame. He concludes that the proportion of individuals who experience positive changes is small, perhaps 10%, but that the positive changes are related to the provision of long term security, relationships based on empathy and person centred care. Nonetheless, Kitwood warns of the danger of romanticising the condition, "treating it as a happy journey or a path of discovery" (Kitwood, 1995), but instead suggests a compromise between despair and optimism.

Orrell and Woods (1996) contrast psychological therapies with one of the most commonly used pharmacological therapy in dementia and conclude that although psychological therapies are "non-toxic, safe and unlikely to require psychiatric supervision" they are nonetheless not as frequently utilised as medication. The authors discuss reasons for this situation, and conclude that psychological interventions are not widely applied due to lack of rigorous scientific research to support their efficacy.

**Reality orientation**

Woods and Roth (1996) write that reality orientation is the "most extensively evaluated psychological approach to dementia". Reality orientation was developed by Laulbee and Folsom (1966), based on the belief that dementia can be worsened by environmental under stimulation (Wallis, Baldwin and Higginbotham, 1983). Reality orientation consists of verbal and visual repetition of key information such as time, date, names of relevant others and functions of everyday items. The aim of this therapy is to increase motivation and reduce dependency through the use of cued recall (Stokes and Goudie, 1990), and to mitigate the disorientation that often accompanies dementia and therefore to reduce the levels of distress experienced by the sufferer (Morton and Bleathman, 1991).

Powell-Proctor and Miller (1982) make a distinction between informal and formal reality orientation. Informal, 24-hour reality orientation is designed to be carried out at all times by the care providers. Continual prompts and reminders are integrated into the activities
of daily living, through everyday communication. Large clocks, pictures and calendars are located in the environment, and individuals are encouraged to make reference to these. Formal or classroom reality orientation usually involves a small group of individuals meeting daily for a short period of time. The meetings are held in a "reality orientation classroom" (Powell-Proctor and Miller, 1982), and information related to time, place and relevant persons is repeated.

Stokes and Goudie (1990) argue that a high quality reality orientation environment would also include social activities, environmental adaptation to aid the individual, reminiscence and recognition of each individual's unique needs. They assert that within reality orientation sessions, facilitators would appreciate that poorly expressed emotions are often present and these would be responded to sensitively. Therefore, there is much overlap between reality orientation and other psychological therapies such as reminiscence and resolution therapy.

Wallis et al (1983) conducted a randomised controlled trial of reality orientation therapy. The trial lasted for three months, and individuals in the reality orientation group received five half-hour sessions each week. Therapy consisted of repetition of information about time, place, weather, relevant persons and names and function of everyday items. Those in the control condition chose from a variety of group and individual activities, in which the same proportion of time as the treatment group was spent. Visual orientation information was placed on the walls around the room, but no specific attention was drawn to this information. Two outcome measures were used to evaluate changes, a behavioural measure of functioning and a scale assessing cognitive abilities. Ratings were made by nurses and occupational therapists, blind to the treatment condition. The ratings were taken on four occasions, before the start, two weeks into the treatment, at the end of the treatment and one-month post treatment. The authors conclude that the participants benefited from both the treatment and control condition and overall greater cognitive than behavioural improvements were observed. The authors suggest that the larger improvement observed on the cognitive rating scale may be due to the confinement of the
therapy to a classroom situation. They conclude that if reality orientation was delivered in a 24-hour form, improvements may be observed in behavioural functioning.

There are a number of methodological issues to consider when drawing conclusions from this research. Spector, Orrell, Davies and Woods (1999) point out that the participants in this research project were long stay patients who were either "demented or withdrawn" (Wallis et al, 1983). Furthermore, there were a high number of participants who did not complete the therapy. 22 out of the original 60 participants were not included due to death, physical illness, refusal, could not be found or had visitors when the group was due to start.

Several reviews of reality orientation have taken place. Woods and Britton (1985) concluded that the therapy produces some improvements in verbal orientation but that changes are minimal in other areas of functioning. They speculated that the benefits in any particular setting may depend upon interactional process of staff and clients. Holden and Woods (1995) reviewed 21 controlled studies including 677 people with dementia. The duration of intervention ranged from 3 weeks to a year. Reality orientation produced improvements in verbal orientation in comparison with no treatment. They concluded that behavioural change was "achieved when reality orientation was implemented effectively and responsively". Spector et al (1999) conducted a meta-analysis of all the random controlled trials of dementia (6), with a total of 125 participants. Measures of cognitive functioning were available for all 125 of the participants, and these showed a significant positive effect. The same positive effect was noted for behaviour although fewer behavioural ratings were made (in total 48 participants). They concluded that reality orientation had a significant positive effect on both cognition and behaviour.

Some authors have expressed criticism of reality orientation therapy. For example, Dietch, Hewett and Jones (1989) consider reality orientation to be an aversive approach for some clients. They argue that for some individuals with dementia the constant
repetition and relearning of information pertinent to orientation may lead to frustration, anxiety, depression and lowering of self-esteem. Butler and Lewis (1977, cited by Dietch, Hewett and Jones, 1989) argue that confusion can provide a defence against the reality of cognitive decline and can therefore be considered as adaptive in some circumstances. They argue that reality orientation can be considered as an attempt to bring individuals back to an "intolerable reality" (Dietch, Hewett and Jones, 1989). They cite three short case examples of individuals who became distressed when attempts were made to orientate them to the present day.

In conclusion, although studies have tended to employ small numbers of participants, or examine only classroom reality orientation which ideally should be in addition to the 24 hour process (Hanley, McGuire and Boyd, 1981), encouraging improvements in cognition and behaviour have been observed. Nonetheless, the work of Dietch et al (1989) indicates that the approach is not suitable for all.

**Reminiscence therapy**

Reminiscence is the "process of recalling past events and experiences" (Goudie and Stokes, 1990). The therapy is based in part, on the life review theory (Butler, 1963, cited by Spector, Orrell, Davies and Woods, 1999) in which past experiences are recalled in order to put life events and experiences in perspective as preparation for one's own death. As remote memory is often the last to deteriorate in dementia (Spector et al, 1999) it is thought that recall of past events can provide a beneficial means of communication. Erbersole (1978, cited by Spector et al, 1999) outlined some of the therapeutic factors which may be involved in reminiscence therapy such as memory stimulation, sharing across generations, self actualisation and identification with peers.

A limited number of authors have tried to evaluate the effectiveness of reminiscence therapy. Head, Portnoy and Woods (1990) evaluated the effectiveness of a 6 week reminiscence therapy group at two day centres (A and B) for older adults with cognitive impairments. A was a specialist day centre for older adults with cognitive impairments,
whereas B was run for individuals living in a long stay "geriatric" hospital. Non participant observations were made during the reminiscence session and during a structured activity session held on the same day. Ten of the 16 group members were selected for observation from the two groups on the basis of demonstrating clinical signs of dementia. In day centre B, reminiscence had a clear effect with significantly more contributions made by the group members than found during the alternative activity session. In day centre A there was no clear increase in contributions during the reminiscence group. The authors suggest that one reason which could explain the lack of impact in day centre A, was that the alternative activity session showed a higher baseline of interaction than in centre B. The authors conclude that many factors influence the effectiveness of reminiscence therapy, and that the therapy will have most value in certain settings, such as those that have low engagement levels.

Baines, Saxby and Ehlert (1987) conducted a randomised controlled trial of reminiscence therapy and reality orientation with 15 older adults showing signs of cognitive impairment. All participants were randomly assigned to one of three groups (reminiscence, reality orientation and control). The group that received reality orientation prior to reminiscence therapy showed improvements in both cognitive and behavioural measures that were not found in the other groups. However, caution must be exercised when examining the results of this study for a number of reasons. First, the number of participants in each condition was small (5). Second, the same staff conducted both the reality orientation and reminiscence therapy. Spector et al (1999) point out that this may have led to the staff mixing elements of the therapies in the absence of clear therapeutic protocols for the groups.

Goldwasser, Auerbach and Harkins (1987) examined the effects of reminiscence therapy contrasted to either a supportive group therapy or a no treatment control group. Twenty seven individuals with a diagnosis of dementia participated in the evaluation. Three assessment measures were utilised in the study, a brief cognitive measure, an assessment of depression and a behavioural measure. Each group was run for half an hour twice
weekly for a period of five weeks. The measures were taken on three occasions, before the start of the therapy, one and five weeks after the intervention.

The results indicated that the reminiscence therapy group showed greater improvements in the level of depression than observed in the other two groups. However, it is of note that the reminiscence participants had higher initial scores of depression than found in the other two groups. It is therefore possible that the reminiscence group had much more scope for improvement that the others. No significant differences were observed in either cognitive or behavioural functioning of any of the participants.

Again, there are several issues to be remembered when evaluating this study. First, the measure of depression utilised in the study was the Beck Depression Inventory (BDI) which asks the individual to recall their mood during the last two weeks. This measure is not commonly used in dementia care, and it is worth considering how accurate self report measures are with populations that may have impairments in short term memory. Sunderland, Alterman, Yount, Hill, Tariot, Newhouse, Mueller, Mellow and Cohen (1988) argue that such rating scales often require cognitive capacities beyond the level of many clients with dementia (e.g. feelings of guilt and insight).

Second, as in the Baines et al (1987) study, the same staff conducted both the reminiscence therapy and social support groups. It is therefore possible that this could have led to carry-over effects between the two groups.

In conclusion, reminiscence therapy has shown encouraging signs of its utility with this client group. Increases have been observed in behavioural, cognitive and functional measures although these have yet to be replicated. Coleman (1986) argues that much research focuses on the cognitive and activity benefits of reminiscence and neglects the wider issues of psychological adjustment, such as the maintenance of identity and expression of emotion.
Validation therapy

Validation therapy is based on the premise of life review, which asserts that all individuals as they reach the end of their lives begin a process of reviewing and working through unsolved conflicts in order to prepare for death (Butler, 1974 cited by Morton and Bleathman, 1991). It is assumed that individuals with memory impairments are handicapped in this process as they may not have access to certain memories and have experienced changes in their sense of self.

The therapy was developed by Feil (1982) and has the underlying principle that there is meaning underlying confused behaviour and the goal is to communicate with a person in their own terms (Stokes and Goudie, 1990) in order to relieve distress and restore self worth (Morton and Bleathman, 1991). The therapist "validates" the individual as they make an effort to understand the feelings behind the confused speech and behaviour.

Stokes and Goudie (1990) write that validation therapy is not "appropriate for people suffering from Alzheimer's Disease or multi-infarct dementia, with the possible exception of when dementia is in the earliest and therefore mildest stages". Despite this viewpoint, there has been an increase in interest in using this approach (Woods and Roth, 1996). The research literature supporting its utility in dementia care is small, with only a few studies cited in the literature.

Morton and Bleathman (1991) conducted a study investigating a validation therapy group for people with dementia. Five participants were invited to join a weekly validation therapy group that lasted for 20 weeks in total. A rigid structure was followed for each session, beginning with a welcome, a group song, discussion chosen to reflect shared feelings (anger, separation or loss) and a closing song. It was hoped that the discussion provided an opportunity for group members to discuss unresolved conflicts and feelings. Participants developed roles within the group such as "welcomer" or "songleader". They selected measures of communication, mood and behaviour as a basis on which to evaluate the efficacy of the intervention. Unfortunately, one of the participants died...
during the trial and another refused to attend, leaving only three participants in the group. The results showed an increase in verbal interaction after the completion of the group for two of the participants and an increase in the mean length of interaction was also observed. The authors conclude that validation therapy had sufficient impact on social interaction to justify further research, but do not make any further claims about the efficacy of the treatment.

Toseland, Diehl, Freeman, Manzanares, Naleppa and McCallion (1997) evaluate the use of validation group therapy in dementia. They randomly assigned 88 residents of four nursing homes to three conditions, validation therapy, social contact group and a control group that received usual care. All of the participants were judged to have at least a moderate level of dementia and to display "problem behaviours", such as aggression, restlessness or disruptive vocalisations. Measures were taken before the intervention, three months and one year later. The nursing staff reported that those individuals who received the validation therapy showed less aggressive behaviour and were not as depressed as those in the other two conditions. However, non-aggressive "problems behaviours" were reduced for participants of the social contact and control group but not for those who took part in the validation group. They conclude that the study indicated limited success of validation therapy for individuals with dementia.

Resolution therapy
Resolution therapy is based on the principle that confused behaviour and expression are an attempt by the person with dementia to "make sense of the here and now” or represent forlorn efforts to express need” (Stokes and Goudie, 1990). This differs from validation therapy, where the confused expression is thought to represent an attempt to come to terms with past events. This therapy draws on Rogerian person centred counselling skills (Cheston, 1998) of reflective listening, warmth and acceptance. They argue that there is a need to acknowledge the person with dementia’s emotional experiences as they make sense of the reality of their condition and their situation.
The therapy aims to help the individual find ways to meet their emotional needs and cope with their feelings. However, there are no studies to date that the author is aware of that evaluates the utility of this approach.

**Cognitive behavioural therapy**
Teri and Gallagher-Thompson (1991) discuss the utility of cognitive-behavioural interventions for treating depression in individuals with Alzheimer's disease. Bonder (1994) asserts that depression is one of the earliest reactions to a diagnosis of dementia. Cognitive theory is based on an assumption that depression is the result of negative perceptions of the self, others and the future. Behavioural theories of depression suggest that depression is a learnt response "maintained through a series of positive and negative reinforcement contingencies" (Teri and Gallagher-Thompson, 1991). The authors suggest that these two theories can be combined and utilised with individuals suffering from dementia. They discuss two separate treatment protocols, one with a cognitive emphasis aimed for those in the earliest stages of dementia and the second with a behavioural emphasis for those in the moderate to severe stages of dementia. The cognitive intervention consists of 16-20 individual sessions, with concurrent phone contact with relatives to explain the principles of the therapy. The content is similar to that used in non-impaired populations, but with adaptations to recording schedules, simple homework tasks, provision of a notepad to make notes during the sessions and an audiotape of the session to facilitate memory. Termination of therapy is staggered and booster sessions are offered to assess how well the client is coping. The behavioural intervention aims to modify aversive experiences and increase an individual's level of rewarding experiences. The intervention includes both the individual with dementia and the carer. Although the authors do not present any research data to support these protocols, they argue that they have been effective in clinical practice. They describe reductions in questionnaire measures of depression. In summary, this approach to depression in dementia is promising, but currently there is only limited information to support its efficacy.
Dynamic Psychotherapy

Hausman (1992) asserts that unresolved internal conflicts emerge in old age that make demands on ego resources and defences. The author suggests that ego resources and defences are weaker in people with dementia as the disease progresses and this leads to the development of emotional problems. Furthermore, the sense of mastery over one's life is considered important to mental health, and the sense of control is often lost in people with dementia along with an increase in helplessness, fear and dependency (Hausman, 1992).

Hausman (1992) states the aims of the therapy are to build a relationship in which the client feels cared for, provide an emotional outlet, increase self esteem, increase the client's coping skills, sense of control and ability to grieve losses of role, cognitive capacities and important relationships. Furthermore, it is hoped that insight is developed and mature and productive defences are maintained and unhelpful defences are weakened.

Hausman (1992) provides case study evidence of the utility of dynamic psychotherapy with this client group. The case of Mr D is reported, a client with Alzheimer's disease. The author claims that during his year of therapy, Mr D was able to realise many of the goals of psychodynamic therapy, such as feeling cared for and valued in the therapy relationship. The therapy provided an emotional outlet and Mr D was successfully able to grieve for his wife and the loss of his career. The author concludes that Mr D was able to retain "coping skills and role functioning much longer than would have been expected if one judges from his mental state examination" (Hausman, 1992). The author concluded that the case study evidence indicates the utility of psychodynamic therapy with some older people suffering from dementia.

Conclusions

Reality orientation and reminiscence therapies appear to be efficacious in dementia care. Other approaches, such as validation, resolution and dynamic and cognitive-behavioural
therapies are less well researched and the limited evidence to support them is largely based on a small number of individuals.

The impact of many psychological interventions in dementia appears to be relatively short-lived. For example, Woods and Roth conclude that there is little evidence of the impact of reminiscence therapy after the termination of group sessions and Baines, Saxby and Elhert (1987) found that the improvements obtained by reality orientation were lost in the following month after the termination of the reality orientation group.

However, as dementia is often accompanied by emotions of depression, anxiety and fear psychotherapeutic approaches that attempt to resolve these feelings should be given priority. Although limited support for these approaches is available, psychotherapy should be considered appropriate for individuals with dementia (Bonder, 1994), and not withheld due to concerns that individuals are unable to benefit. Clinical examples have shown that this is not the case, and further research is necessary to establish the efficacy of these interventions.

References


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Clinical

Dossier
Adult Mental Health Summary of Placement Experience

Placement location: Graylingwell Hospital and Midhurst Community Mental Health Team

Trust: Chichester Priory Care Services


Supervisor: Louise Norinder and Bill Reavley

The placement was split between a psychiatric hospital and a community mental health team. Settings included an acute psychiatric ward, a ward for people with enduring mental health problems and a community mental health team.

Methods of assessment included interviews, standardised questionnaires (e.g. BDI) and psychometric testing. Interventions were within a cognitive behavioural framework but drew on a range of approaches including motivational interviewing, bereavement therapy and neuropsychological models. A wide range of experience with clients was obtained, including clients with depression, anxiety (posttraumatic stress disorder, agoraphobia, flight phobia), eating disorders, borderline personality disorders, sexual difficulties, memory and concentration problems. Interventions were conducted with individuals, families and groups. A total of nine clients were seen individually, one as a couple and an average of six clients were seen in group sessions.
Copy of Adult Mental Health Placement Contract

PSYCHD IN CLINICAL PSYCHOLOGY

ADULT CORE PLACEMENT

TRAINEE PLACEMENT CONTRACT - October 1996

LOCATION: Chichester Priority Care Services NHS Trust.

TRAINEE: Carolyn Graham.

PLACEMENT SUPERVISOR: Louise Norinder.

ADDITIONAL SUPERVISOR: Mr W Reavley.

REGIONAL CLINICAL TUTOR: Mary John.

AGENCY DESCRIPTION: Chichester Priority Care Services is a Mental Health and Community Service under the auspices of the NHS Trust. It provides help for people with mental health problems, including inpatient, day patient and outpatient care, from a variety of hospital and community settings. The service is staffed by a range of professionals including psychologists, psychiatrists, psychiatric nurses, occupational therapists, physiotherapists and social workers. Areas of mental health dealt with by the psychology department include Child and Family Services, Adult Mental Health, Learning Disabilities, Rehabilitation and Alcohol and Substance Abuse.

CONDITIONS OF PLACEMENT

1. The trainee will work within the Trust from 15 October 1997 to 3 April 1998 for 3 days each week. Twelve and a half days of annual leave can be taken during this time. The trainee will be based at Graylingwell Hospital.

2. One hour 1:1 contact each week will be allocated to supervision in order to review progress of current activities and reflect on issues arising. (As per Minimum Standards, page 113, Clinical Placement Handbook). Supervision will include presentation of patients, tape recordings of clinical sessions and pre and post discussions with supervisors. An additional 1-2 hours per week will be for joint supervision with the placement or additional supervision.

3. Friday afternoons to be allocated to trainee’s private study (one session).

AIMS OF PLACEMENT

a. To provide trainee with experience of the full range of clients referred to adult services.

b. To expose trainee to a wide variety of service settings.
2. **Range of clients**

The trainee should gain experience of working with the full range of clients referred to adult services.

i) Age - The trainee will see clients across the age span, covering late adolescence and young adulthood, middle and later ages up to 65.

ii) Gender - The trainee will see an appropriate mix of people.

iii) Ethnic background - If possible, the trainee will have some level of clinical contact with at least one person from a different ethnic and/or cultural background.

3. **Neuropsychology and psychometric assessment**

The trainee will gain experience of using psychometric assessment through observation of qualified psychologist and independent client assessment. This will include a WAIS-R, Weschler Memory Scale and other relevant tests.

4. **Structure of therapy and intervention**

i) Individual therapy work - The trainee will gain direct experience of individual client work.

ii) Therapy work with couples and/or families - If appropriate, the trainee will gain indirect experience of this type of therapy through observation of qualified clinicians.

iii) Group therapy work - The trainee will gain direct experience of group work through co-facilitating a therapy group with a qualified clinician.

5. **Settings**

The trainee should gain experience of working in as wide a range of settings as possible, for example:

- Psychology Department.
- Community Mental Health Teams.
- Primary Care Settings.
- Day Centres.
- Group Homes.
- Inpatient wards (acute long stay and rehabilitation)
- Client’s homes.

The range of settings should include other agency facilities.

a. To enable trainee to gain experience of using the theory and methods of cognitive behavioural psychotherapy to work with adult patients and their problems.
OTHER EXPERIENCES

1. The trainee will write psychological reports, case notes and letters as required.

2. The trainee will keep administrative records consistent with the requirements of the department.

3. The trainee will attend and participate in departmental meetings as well as meetings and other professional development activities appropriate to the placement.

4. The trainee will keep a record of experiences gained in the placement.

5. If possible, the trainee will be involved in teaching or training.

REVIEW

Meetings between the trainee, the placement supervisor and the Regional Clinical Tutor at the middle and end of the placement will be used to review the trainee's progress towards achieving goals and to renegotiate the contract if required.

Carolyn Graham  Louise Norinder

Graham  Norinder
Learning Disabilities Summary of Placement Experience

Placement location: Richmond Royal Community Healthcare Hamlet
Trust: Kingston and District Community NHS Trust
Dates: April 1998 - October 1998
Supervisor: Andrew Adlem

The placement was within a psychology department for people with learning disabilities. Experience was gained working within community teams, an intensive support team for people with challenging needs, residential homes and day centres. Methods of assessment included interviews with clients, families and carers, behavioural observation, standardised questionnaires (e.g. Motivation Assessment Schedule, Vineland Adaptive Behaviour Schedule) and psychometric testing. Interventions were within a behavioural framework but drew on a range of approaches including cognitive approaches, systemic theories and dynamic models. A wide range of experience with clients was obtained, including clients with anger management problems, challenging needs, autism and sexual abuse. Interventions were conducted with individuals, staff groups and carers. A total of eight clients were seen during the placement.
PSYCHID IN CLINICAL PSYCHOLOGY
LEARNING DISABILITY CORE PLACEMENT
TRAINEE PLACEMENT CONTRACT – APRIL 1998

Location: Kingston and District Community NHS Trust

Placement supervisor: Andrew Adlem
Additional supervisor: Ewa Rula

Conditions of placement

1. The trainee will work within the trust from 22 April 1998 to 2 October 1998 for 3 days each week. Twelve and a half days of annual leave can be taken during this time. The trainee will be based at Richmond Community Healthcare Hamlet.
2. Two hours 1:1 contact each week will be allocated to supervision in order to review progress of current activities and reflect on issues arising (as per minimum standards).
3. Alternate Fridays will be allocated to trainee’s private study.

Aims of placement

1. To participate in a) CTPLD meetings b) psychology speciality meetings c) learning disabilities special interest group d) continuing professional development events and e) departmental meetings.
2. To gain experience of a range of intervention approaches and in particular at least one client from a cognitive behavioural perspective.
3. To work with a range of people with learning disabilities including a) varied age group b) severity of learning disability c) different living situations and d) different ethnic origins.
4. To complete at least one functional assessment of challenging behaviour in a person with learning disabilities.
5. To complete an assessment of learning disability including a) an assessment of cognitive functioning and b) an assessment of adaptive behaviour.
6. To gain experience in a wide range of presenting problems including a) challenging behaviour b) anxiety or depression c) interpersonal issues (anger management, assertiveness etc).
7. To complete a service related research project.

Other experiences

1. The trainee will write psychological reports, case notes and letters as required.
2. The trainee will keep administrative records consistent with the requirements of the department.
3. The trainee will keep a record of experiences gained in the placement.

Review

Meetings between the trainee, the placement supervisor and the Regional Clinical Tutor at the middle and end of placement will be used to review the trainee’s progress towards achieving goals and to renegotiate the contact if required.

Carolyn Graham
Clinical Psychologist in training

Andrew Adlem
Consultant Clinical Psychologist
Child, Adolescent and Family Summary of Placement Experience

**Placement location:** West Park Hospital, Epsom  
**Trust:** Surrey Heartlands NHS Trust  
**Dates:** October 1998 - April 1999.  
**Supervisor:** Penny Bebbington and Shona Lowes

The placement was split between a psychology service for the under 5's and a child and adolescent psychiatry team.

Methods of assessment included interviews, standardised questionnaires (e.g. Children's Culture Free Self Esteem Inventory), behavioural observations and psychometric testing. Interventions were within a cognitive behavioural framework but drew on a range of approaches including developmental models and attachment theories. A wide range of experience with children and adolescents was obtained, including clients with sleep problems, encopresis, feeding problems, histories of abuse, physical pain, difficulties adjusting to parental divorce, low self esteem, blood-injury phobia and attention deficit hyperactivity disorder. Interventions were conducted with individuals and families. A total of thirteen clients were seen throughout the placement.

In addition to clinical work, a presentation on sibling rivalry was given to a health visitor's meeting and a presentation on narrative approaches in child and family was given to a psychology department meeting.
CONTRACT FOR PLACEMENT FOR EXPERIENCE WITH
CHILDREN AND ADOLESCENTS FOR THE
UNIVERSITY OF SURREY DOCTORATE IN CLINICAL PSYCHOLOGY

LENGTH OF PLACEMENT: 6 months
14.10.98 - April 1999.

NAME OF TRAINEE: Carolyn Graham.

NAMES OF CO-SUPERVISORS: Penny Bebbington, Shona Lowes

ADDRESS: Psychology Department, West Park Hospital, Surrey Oaklands
NHS Trust, Horton Lane, Epsom, Surrey KT19 8PB

TEL: 01372 203302

There will be a total of 2 hours each week supervision with both supervisors.
There will be ½ day a week study time, and 3 days special study leave during the
placement.

AIMS OF THE PLACEMENT

1. To achieve at least an acceptable standard in the core competencies as applied to
   Children and Adolescents as specified in the Clinical Placement Handbook.

2. To introduce the trainee to this client group and give experience within the full age
   and problem range.

3. To develop her awareness of their needs.

4. To have experience of the range of possible psychological assessments, therapeutic
   interventions and theoretical models.

5. To gain experience of the wider system of inter-professional and inter-agency net
   working.
OBJECTIVES

1. To observe children within the normal range of development in a variety of settings, individual and group.

2. To enable the trainee to communicate effectively with children at different developmental levels.

3. To select, use and interpret norm referenced and criterion referenced tests.

4. To plan and undertake at least part of therapeutic interventions in one model.

5. To develop formulation skills and communicate the formulation method and outcome of all interventions in writing.

6. To present a psychological intervention to multi-disciplinary group.

7. To observe the work of other professionals in multi-disciplinary teams to gain understanding of the interrelationship.

8. To give experience of child protection issues, children with psychiatric diagnosis.

METHODS

A: Professional Development

1. To attend meetings of the Psychology Department held on alternate weeks.

2. To attend a range of meetings including the Child Clinical Psychology service and the District Child Development Team and the Child and Adolescent Psychiatry Team.

3. To attend a Child S.I.G. Meeting.

4. To present a case report to a multi-disciplinary group.

5. To give a Seminar to the department.

6. To develop awareness of Child Protection procedures.

B: Visits and Observations

1. To spend at least one hour observing children in a play group and a nursery.

2. To observe other professionals working therapeutically with children individually and in groups, including a Speech & Language Therapist, a Physiotherapist and Occupational Therapist.
3. To observe the work of another Psychologist in assessment and therapy sessions.

4. To attend sessions of the Junior Opportunity Group run for multiply disabled children.

5. To visit a special school or unit which includes children with special educational needs.

C: Assessment

1. To administer three psychological tests of norm-referenced tests including the WISC III and a pre-school test of development for 1 pre-school, 1 middle years child and 1 older child.

2. To take a detailed history of a psychological problem using a pre-planned structure.

3. To carry out an observational assessment using a structured format as a basis for behavioural analysis.

4. To gain clinical experience of a variety of problem areas, including those of particular interest as ADHD.

D: Intervention

1. To carry through the process of treatment in the agreed number of selected cases.

2. To be included in working with a child from a different ethnic background.

3. To participate in family interview and therapy sessions.

4. To work jointly with supervisors in assessment and intervention of a range of individual cases.

E: Teaching

1. To assist in a Workshop run for Health Visitors designed for sharing skills about family relationship problems.

Penny Bebbington
Clinical Psychologist

Carolyn Graham
Clinical Psychologist in Training

Shona Lowes
Clinical Psychologist

Supervisors

14.10.98.
Physical Health Placement Summary Experience

Placement location: Kingston Hospital

Trust: Kingston Hospital NHS Trust / Kingston and District NHS Trust.


Supervisor: Ann Gold, Anna Iwinicki and Catherine Dooley.

The placement included work within three specific areas; a pain management service, diabetes service and chest clinic within a general hospital setting.

Methods of assessment included interviews and standardised questionnaires (e.g. Well-being questionnaire). Interventions were within a cognitive behavioural framework and models of health and illness were utilised (e.g. self-regulatory model and illness perceptions). A wide range of experience with clients was obtained, including clients with chronic pain, diabetes and asthma. Psychological issues included the management of chronic pain, difficulty adjusting to physical conditions / physical disability, depression, posttraumatic stress disorder, agoraphobia, sexual difficulties and the misuse of pain medication. A total of ten clients were seen individually. Experience was gained in working therapeutically with clients from different cultural and ethnic backgrounds.

In addition to individual work, experience was gained co-facilitating a pain management group. A client information leaflet about anxiety and asthma was devised and piloted.
Physical Health Placement Contracts - Pain Management

CONTRACT FOR PLACEMENT IN PAIN MANAGEMENT SERVICE

Location: Pain Management Service
Kingston Hospital NHS Trust
Galsworthy Road,
Kingston upon Thames
Surrey KT2 7QB

Telephone: 0181 546 7711 extension 2563
Fax: 0181 546 2199

Length of Placement: 6 months
21st April 1999 – 1st October 1999

Name of Trainee: Carolyn Graham

Name of Supervisor: Ann Gold

Time in Placement: Approximately 3 sessions per week.

Supervision: 1 hour each week with Ann Gold, generally on
Thursday morning but flexible depending on other commitments.

Aims of Placement

1. To achieve a broad understanding of the chronic pain syndrome and the contribution Clinical Psychologists can make to clients in this setting.

2. To introduce the trainee to this client group and provide experience of a range of problem areas and therapeutic approaches.
Objectives

1. To initially spend some time reading appropriate psychological literature suggested by the supervisor, to gain specialist knowledge relevant to this client group.

2. To observe Ann Gold carrying out direct assessment and intervention with a range of clients referred to the Pain Management Service.

3. To gain direct experience with at least 3 individual clients, carrying out initial structured interviews, formulating possible interventions and carrying out individual therapy if possible. The trainee will have direct experience with at least one client from a different ethnic/cultural background.

4. To gain experience in using and interpreting a range of questionnaires and rating scales relevant to chronic pain.

5. To observe individual hypnotherapy sessions carried out in the Pain Management Service by a qualified practitioner and under supervision gain some direct experience of the use of imagery and hypnotherapy techniques in controlling pain.

6. To observe the Pain Management Group Programme and if possible, co-facilitate at least one session of this programme.

7. To write psychological case-notes, reports and letters as appropriate.

8. To attend and participate in multi-disciplinary team meetings and other professional development activities which occur during the placement.

9. To give a presentation to the multidisciplinary team, either of an individual psychological intervention, or a summary of a topic relevant to chronic pain from the psychological literature.

10. To be introduced to the research initiatives within the Pain Management Service.

Contract agreed by: 

Carolyn Graham

Ann Gold
For Kingston Hospital NHS Trust
Specialist Placement Contract: Diabetes and Neuropsychology Contract

Specialist Health Psychology Placement Contract for Carolyn Graham  April 1999 – October 1999

DIABETES DAY UNIT WORK/NEUROPSYCHOLOGY ASSESSMENT

A. Diabetes Work

- As part of her Health Psychology Specialist placement Carolyn will spend approximately 1 session per week working in the Diabetes Day Unit at Kingston General Hospital. Carolyn will be supervised for this work by Anna Iwnicki. As part of this work she will have the opportunity to observe Anna carrying out direct assessment and intervention with people diagnosed as having insulin dependent diabetes mellitus and (if referred during her placement) non-insulin dependent diabetes, during a monthly diabetes clinic.

- Carolyn will have the opportunity to complete at least one assessment of a new client with either insulin dependent diabetes or non-insulin dependent diabetes. She will provide ongoing therapy with a maximum of 3 clients.

- There will be opportunities (time permitting) to observe consultation sessions with the nurse specialist in diabetes which take place approximately once every 2 months.

- Carolyn will have exposure to, and an opportunity to integrate into her practise, models of health psychology such as the Health Beliefs model. There will be an opportunity to use a number of rating scales or questionnaires relevant to diabetes.

- Supervision for her work in the Diabetes Day Unit will be provided fortnightly for 1 hour. Anna Iwnicki is also available outside these times if something arises relating to clinical work in the Diabetes Day Unit.

B. Neuropsychology Assessment

- Carolyn will have an opportunity to observe a neuropsychological assessment. In addition she will carry out a neuropsychological assessment on at least 1 client, interpret the findings and write a full report for the referrer. This work will be supervised by Anna Iwnicki.

Contract agreed by

Carolyn Graham

Dr. Anna Iwnicki

Date: 14/5/99

cc Catherine Dooley/Ann Gold
Older Adults Summary of Placement Experience

Placement location: Guildford Community Mental Health Team for the Elderly
Trust: Surrey Hampshire Borders NHS Trust
Dates: October 1999 - April 2000
Supervisor: Ajay Kapoor

The placement was based in a community mental health team for older adults. Settings included individual's homes, residential homes, day centres and an acute psychiatric ward.

Methods of assessment included interviews, standardised questionnaires (e.g. Geriatric Depression Scale, Maudsley Obsessive Compulsive Inventory) and psychometric testing. Interventions were within a cognitive behavioural framework but drew on a range of approaches including loss and attachment, and neuropsychological models. The ranges of presenting problems included clients with obsessive-compulsive disorder, depression, agoraphobia, complicated grief reactions, dementia, carer stress, memory and concentration problems. Interventions were conducted with individuals, families / carers and groups. A total of ten clients were seen throughout the placement. In addition to the direct client work, organisational work examining how the needs of 65-70 year olds were met by the service, and looking at future alternatives was undertaken.

A presentation on psychotherapeutic approaches in dementia was presented to a local psychology special interest meeting.
Older Adults Placement Contract

TRAINEE: Carolyn Graham  
SUPERVISOR: Ajay Kapoor  
DATES: 13th October to 24th March 2000  
LOCATION: Surrey Hampshire Borders Health Trust

The trainee will acquire the following skills/experience:

- Work with clients across a wide range of ages between 65-85+, with supervised caseload of approximately 10 clients during the placement.
- Work with clients in as wide range of settings as possible including assessment and continuing care wards, day hospitals, clients homes and day centres.
- Work with clients presenting a variety of problem areas including depression, cognitive change with age, dementia, adjustment and adaptation difficulties, mortality, stroke and challenging behaviour.
- Develop neuropsychological assessment skills within the context of a service designed specifically for older adults.
- Ability to modify therapeutic approaches to meet the needs of older people.
- Knowledge of therapies devised specifically for older people.
- Work with clients suffering from physical health problems.

Communicate clearly the formulation, method and outcome of psychological assessment, interventions, both orally and in written report.

Work with other disciplines in a multi-disciplinary framework and developing good co-operative relationships with them.

Attendance at training events related to the speciality.

Supervision will be for one and a half hours contact per week with additional informed contact as necessary.

A formal review of the placement will occur half-way through the placement. Full written feedback will be provided at the end of the placement.

Carolyn Graham  
Clinical Psychologist in training  
Ajay Kapoor  
Clinical Psychologist
Neuropsychology Summary of Experience on Placement

Placement location: Atkinson Morley's Hospital and the Wolfson Neuro Rehabilitation Centre

Trust: St George's Hospital Trust


Supervisor: Martin van den Broek and Geoff Marshall

The placement was based within a neurological rehabilitation centre and a neurosciences hospital. Clients were seen as in-patients during the three to six months rehabilitation programme, or during a short stay in hospital. Outpatients included those referred by neurologists and neurosurgeons for assessment after brain injury or illness.

Methods of assessment included interviews with client and relatives and psychometric tests. Experience was gained in a wide range of tests including the WAIS-III, WMS III, Behavioural Assessment of the Dysexecutive Syndrome (BADS) and Attention Control Test (ACT). Interventions were within a neuropsychological and cognitive behavioural framework. Clients with diverse problems were assessed including stroke, head injury, epilepsy, meningitis, encephalitis, anxiety/panic disorder, depression and inappropriate behaviour. Interventions were conducted with individuals and families. A total of fourteen clients were seen individually. Experience was gained in assessing individuals from different ethnic / cultural backgrounds.
Neuropsychology Placement Contract

The Wolfson Neurorehabilitation Centre  St George’s Healthcare NHS Trust

Department of Clinical Neuropsychology Regional Neurosciences Centre
Head of Department Atkinson Morley’s Hospital
M.D. van den Broek, PhD, C. Psychol Copse Hill, Wimbledon,
London SW20 0NG

Clinical Psychology Specialist Placement
Neuropsychology Contract

April 2000 - September 2000

Trainee name: Carolyn Graham

Placement supervisors: Martin van den Broek and Geoff Marshall

AIMS
- To develop an understanding of the issues facing people with acquired brain injuries
- To gain practical and academic knowledge of neuropsychology
- To gain knowledge of the clinical psychologist’s role in rehabilitation
- To prepare for the transition from trainee to newly qualified clinical psychologist

GENERAL OBJECTIVES
1) To experience through observation and clinical contact, a wide range of difficulties faced by individuals with brain injury.
2) To develop and refine assessment skills with this client group utilising a wide range of assessment materials.
3) To develop formulation skills drawing on clinical observations and psychometric test data.
4) To gain an understanding of basic neuroanatomy and localisation of brain function.
5) To gain experience of therapy skills with this client group with particular emphasis on cognitive rehabilitation.
6) To gain an understanding of the different roles of members of the multidisciplinary team working in rehabilitation.

SPECIFIC OBJECTIVES
1) To work with clients with a wide range of presenting difficulties including both inpatients and outpatients.
2) To observe at least one neuropsychological assessment, including clinical interview, psychometric testing and client feedback.
3) To complete a minimum of ten neuropsychological assessments independently during the course of the placement.
4) To discuss the neuropsychological formulation process in supervision moving towards independent formulation by the end of the placement.
5) To plan and implement rehabilitation strategies with at least three clients.
6) To learn how to dictate psychological correspondence in preparation for move to newly qualified clinical psychologist.

Carolyn Graham
Trainee
Clinical Psychologist

Geoff Marshall
Clinical Psychologist

Martin van den Broek
Clinical Psychologist
Adult Mental Health Case Report Summary

Psychological Intervention for Adjustment Disorder with Anxiety following a Motor Vehicle Accident

Referral and presenting problem: Mrs D was referred by her GP for "post traumatic stress disorder" following a motor vehicle accident.

Initial assessment: Information was collected from an assessment interview and standardised assessments (BDI, BAI, Impact of Events Scale).

Formulation: Mrs D’s difficulties were conceptualised within a cognitive behavioural framework. Within this model, behaviour, cognitions and physiology interact to produce anxiety reactions. The trauma of the car accident triggered Mrs D’s problems, through the process of classical conditioning. Her automatic negative thoughts produced by her negative beliefs helped to maintain her anxiety symptoms. Cognitive biases such as the overestimation of the possibility of unpleasant events occurring contributed to the maintenance of the problem, and led to avoidance of situations resembling the accident.

Action plan and implementation:
Mrs D was seen for a total of seven sessions over a three month period. Systematic desensitisation, using a hierarchy of feared situations, combined with anxiety management techniques (relaxation, education and guided self dialogue) and identification of unhelpful thoughts.

Outcome:
D made considerable progress during therapy. Her subjective ratings of feared situations showed considerable reductions in anxiety levels. Her intrusive thoughts decreased, as did her level of avoidance.
Learning Disabilities Case Report Summary

Psychological intervention for challenging behaviour

Referral and presenting problem: Mr J was referred by the duty care manager following an abuse strategy meeting. Mr J had a moderate learning disability. Presenting problems included repeated questioning, taking and throwing away items and interpersonal relationships.

Initial assessment: Information was collected from interviews with staff at the residential home and day placement, non-participant behavioural observations and standardised assessment (Motivation Assessment Schedule).

Formulation: Mr J's difficulties were conceptualised within a behavioural framework, utilising the STAR model (settings, triggers, actions and results). This model emphasises the purpose that behaviour serves for an individual, placing importance on environmental events in causing, controlling and maintaining behaviour.

Action plan and implementation: Intervention included both targeting unwanted behaviours for change and encouraging more interaction between Mr J and staff members. Three strategies were used including a daily diary to ensure predictability of routines, enabling Mr J to learn more appropriate ways of engaging in interaction and consistent staff response to repetitive questioning.

Outcome: The daily diary was reported to be a successful strategy and Mr J utilised it to initiate conversations with other residents. Staff reported a decrease in problematic behaviour, although it did not cease altogether. Observations supported this decrease and demonstrated an increase in levels of staff interaction.
Child, Adolescent and Family Case Report Summary

Report of a Psychological Intervention for Faecal Soiling

Referral and presenting problem: Master Simon Day was referred to the service by the health visitor. He was 4 years old. The presenting problem was persistent soiling, aggression and Simon had recently begun to wet himself.

Initial assessment: Information was collected from interviews with Mrs Day, monitoring charts and standardised questionnaire (Pre-School Behaviour Checklist).

Formulation: The case was formulated within a social learning model. This theory places an emphasis on the active nature of learning, the social context in which learning takes place and the role that cognition and meaning often play. Triggering events included the birth of his sister, maintaining factors included the role of attention in reinforcing the soiling and the lack of a consistent approach to his behaviour.

Action plan and implementation:
Behavioural retraining techniques were utilised (limit attention for soiling, positive reinforcement for toilet use, consequences for unacceptable behaviour, regular intervals for bowel emptying, an increase in positive time with both parents), alongside demystification and education.

Outcome:
There was a substantial reduction in soiling. He began to use the potty more frequently, and occasions of wetting ceased completely. Coincidently, Simon became more aware of the social unacceptability of soiling and his peers were becoming more important. Aggression to his sister and other children also reduced.
Physical Health Case Report Summary

Intervention for adjustment to diabetes within a cognitive behavioural and illness perceptions framework

**Referral and presenting problem:** Mr K was referred to the psychology service by the diabetes specialist nurse. Presenting problems included difficulties complying with glucose testing, adjusting to physical complications of diabetes, depression and avoidance of social situations.

**Initial assessment:** Information was collected from interviews with Mr K and the diabetes nurses specialist and dietician involved in the care of his diabetes. Standardised questionnaires were also utilised (Experience of Treatment Benefits and Barriers, HADS & BDI).

**Formulation:** Mr K's difficulties were conceptualised within a cognitive behavioural framework. Difficulties in adjustment to diabetes were formulated using a health and illness representational model allowing for an in-depth exploration of diabetes specific beliefs and how they are linked to illness behaviour.

**Action plan and implementation:** Due to time constraints the issues to be addressed were negotiated and prioritised. The clinical formulation was shared, behavioural experiments were used to test his beliefs about his diabetes, and a graded approach to testing introduced. Thought monitoring, challenging and activity scheduling were also utilised.

**Outcome:** Mr K was seen for eleven sessions over a five-month period. After a short period he began to test his glucose levels with only occasional omissions. He reported feeling more positive and began pursuing personal interests and looking for opportunities to socialise. Changes in the level of depression were noted on standardised measures.
Older Adults Case Report Summary

Neuropsychological Assessment of a client with Parkinson’s Disease

Referral and presenting problem: EV was referred for cognitive assessment by the psycho geriatrician for the CMHT. The presenting problem was a rapid deterioration in EV’s memory reported by his wife but not acknowledged by EV.

Initial assessment: Information was collected from interview with EV, his wife and his son.

Formulation / Hypothesis: A clinical neuropsychological model was used to assess and formulate EV’s difficulties. This is concerned with the behavioural expression of dysfunction. Hypotheses were formulated that could account for the presenting problems which were tested through neuropsychological assessment.

Neuropsychological assessment: Tests of premorbid intelligence and general intellectual functioning were used, alongside tests assessing memory and new learning, verbal fluency, visuospatial skills, reasoning and an assessment of mood.

Outcome: Cognitive deficits were demonstrated in the areas of frontal lobe dysfunction, word finding difficulties and memory. There was insufficient evidence to conclude that EV was experiencing greater cognitive impairment than expected in Parkinson’s Disease. A reassessment in six to twelve months was recommended to monitor future change.
"Evaluating a staff training package on challenging behaviour: Changes in causal attributions and staff satisfaction with training"

Service related research project

Year II

November 1998
Abstract

Objective: The research evaluated a challenging behaviour training package for staff working with people with learning disabilities. The aim of the training was to introduce psychological frameworks for understanding challenging behaviour, possibly challenging existing attributions about the cause of the behaviour. Changes in causal attributions about challenging behaviour were assessed, alongside participant’s satisfaction with the training package.

Design: A two stage, pre and post design was utilised.

Setting: The first training session was held in a community residential home for people with a learning disability and the second session was held on NHS premises.

Participants: Twenty one staff members attended two separate training sessions (nine attended a full day of training, and twelve attended four two hour sessions). Thirteen of the staff members completed both the pre and post training measures.

Main Outcome Measures: Outcome measures were the Challenging Behaviour Attribution Scale (CHABA) and a questionnaire examining satisfaction with the training.

Results: No significant changes on the CHABA were found. Participants found the training interesting and aimed at the right level. Criticisms concerned the lack of time given to the training. Some respondents expressed a wish for further training concerning positive programming and teaching strategies.

Conclusions: The participants expressed satisfaction with the training received, however no significant changes on the CHABA were identified.
Introduction

The relationship between staff attitudes and challenging behaviour amongst people with learning difficulties is an important area that has begun to be researched over the last ten to fifteen years. The behavioural model suggests that challenging behaviour, like other behaviours, are sensitive to the actions of others in the environment. Functional assessments have shown challenging behaviour to be related to the way in which staff behave. For example, Felce, Rep, Thomas, Ager & Blunden (1991) found that lower rates of stereotypy were evident when staff members were in the same room as a client.

The consequences of challenging behaviour are typically mediated by others: for instance an increase or decrease in social interaction, termination of demands, supply of tangible reinforcement and aversive consequences may all follow from an episode of challenging behaviour. Mitchell and Hastings (1998) write "the actions of caregivers of people with learning disabilities have been shown to be crucial to an understanding of the development and maintenance of challenging behaviours ". Therefore, staff responses to challenging behaviour may be usefully examined as part of psychological interventions aiming to reduce challenging behaviour.

Hastings (1995) discussed some aspects of service environments which may explain why staff may respond inappropriately to challenging behaviour. These aspects included an emphasis in staff training on the techniques for managing behaviour rather than understanding it, and the resulting belief that challenging behaviour is to be controlled.

However, it is too simplistic to assume challenging behaviour is caused entirely by staff behaviour. Other environmental contingencies are operating. Mitchell and Hastings (1998) argue that challenging behaviour and staff responses are best considered as a dynamic behavioural system. They cite the example of self injury which occurs in response to demands made by staff (antecedent for client behaviour), staff then respond to the self injury by removing the demands (consequences for client behaviour). When considering the staff perspective, the self injury acts as an antecedent for staff behaviour.
Research dossier: Service Related Research

(i.e. removing demands) which leads to termination of self injury (consequences for the staff member). Thus, the behaviour of staff and service users is enmeshed - the challenging behaviour of clients in turn influences staff behaviour.

An important component of staff responses to challenging behaviour is the emotional component. Staff behaviour towards people with learning difficulties and challenging behaviour may be related to how they experience challenging behaviour (Dagnan, Trower and Smith, 1998). Bromley and Emerson (1995) surveyed a single metropolitan borough and found that respondents reported one of the most significant sources of stress associated with caring is "their difficulty in understanding the person's behaviour, the unpredictability of the behaviour and the apparent absence of an effective way forward". They also found that care staff attributed the causes of challenging behaviour to a mixture of internal psychological states (e.g. stress, anxiety, frustration), past and current environmental factors (e.g. abuse, childhood, reaction to change, lack of staffing) and medical factors (e.g. constipation, pain, PMT). They conclude that the casual attributions concerning factors over which staff have little control were the most commonly held beliefs (e.g. general psychological states, broad aspects of past environments). If the staff member feels that little can be done to change the behaviour, this may well influence their ability to request further assistance. Beliefs in which the staff themselves may exercise some control (e.g. the use of challenging behaviour as communication) were much less common. This research highlights the importance of staff's attributions and beliefs about challenging behaviour, and the role attributions could play in influencing how staff manage such behaviour.

It is against this background that the learning disabilities speciality where the author was based, decided to implement a series of training sessions for staff members working in both day and residential settings for people with learning disabilities. The training aimed to facilitate an understanding of challenging behaviour, rather than techniques for controlling it in isolation. The aim of training was to facilitate understanding of challenging behaviour, consistent with current psychological theories of challenging
behaviour. Causal attributions of challenging behaviour have been hypothesised as changeable as a result of theoretical and practical training, and changes in causal attributions was one of the criteria selected to assess the impact of the training.

A very small number of published studies have attempted to evaluate the effect of training on staff groups. An example of such a study is by Berryman, Evans and Kalbag (1994). They examined the effects of non-aversive behaviour management on the attitudes and understanding of care staff. The non-aversive approach avoids the use of punishment and intrusive interventions, and emphasises the understanding of behaviour in terms of learning history, motivation and social context (e.g. Durand, 1990). This study utilised a questionnaire examining causal attributions, attitudes towards disabled people and participant evaluation of the workshop. They found significant reductions in attributions of emotional and low self esteem causal factors (which are similar to the emotional subscale of the Challenging Behaviour Attributions Scale), and increases in escape/avoidance attributions (similar to the learned behaviour subscale), after training had taken place.

It was hypothesised (Hastings, 1997) that staff undergoing training would begin to:

1) examine causal explanations relating to positive and negative reinforcement (learned behaviour), and environmental contingencies

2) Show less causal attributions concerning emotional and biomedical explanations

These hypotheses will be examined in this study.

Method

Participants and recruitment
Two residential services for people with learning disabilities requested training in challenging behaviour. Both services were residential services for people with learning disabilities, however one service specialised in supporting individuals with challenging behaviour. The specialist challenging behaviour service was invited to attend the four
session training event (4 x 2 hours), and the other service was invited to attend for the whole day event. Nine staff members attended the one day training event, and twelve participants attended the four sessions of training. The training sessions were run by a clinical psychologist and a senior nurse practitioner, both of whom worked for the trust’s Intensive Support Team. The same material was covered in both training events.

Measures

Demographic questionnaire
A brief demographic questionnaire was used to obtain background information about the participants. This questionnaire covered age, sex, job title, experience with learning disabled individuals and training received.

The Challenging Behaviour Attributions Scale (CHABA) (appendix two)
This is a self completion questionnaire, devised by Hastings (1997, revised version 1998). It was designed for research into staff behaviour and for “inclusion with other measures in the evaluation of staff training on challenging behaviour” (Hastings, 1997). It is a 33 item scale, with statements relating to five causal models: learned behaviour (six items), medical/biological factors (six items), emotional factors (seven items), aspects of the physical environment (eight items), and self stimulation (six items). A score for each of these five sub-scales is calculated. For each item staff are asked to rate how likely each explanation of challenging behaviour is. Each rating is assigned a value of (-2) very unlikely, (-1) unlikely, (0) equally likely/unlikely, (1) likely, (2) very likely. Total scores for each sub-scale are calculated by summing the ratings and dividing this score by the number of items in the sub-scale. If a sub-scale has a score below zero, this would suggest that the respondent considers this causal model is unlikely to apply whereas a score above zero suggests that the respondent views this model as applicable in explaining challenging behaviour.
The definition of challenging behaviour used by the service was attached to the questionnaire (see appendix three).

The reliability of the CHABA has been assessed (Hastings 1997) using the internal consistency method. Hastings concludes that the internal consistency for each of the sub-scales, was moderate to good in size (Cronbach's alpha values between 0.65 and 0.87). At present there is no validity measure for the CHABA, given the lack of objective external validation criteria.

Staff satisfaction questionnaire (see appendix four)
This was given to participants at the end of training, along with the second copy of the CHABA. Participants were asked to rate the training on a number of dimensions (e.g. how interesting it was, its relevance etc.). Space was included for participants to add any further comments or suggestions.

Procedure
Staff members attending the training sessions were given a letter outlining the purpose of the evaluation (see appendix one) and requesting completion of the demographic questionnaire and the CHABA Scale. The letter and questionnaire was given at the beginning of the training session. The confidentiality of responses was stressed, and participants were assured that the trainers would not see the completed questionnaires. A copy of the questionnaire sent before the training can be seen in appendix two.
At the end of the training session, copies of the post-training questionnaire (see appendix four) were given out. This questionnaire asked respondents to rate the training across a variety of dimensions, including how interesting, relevant and informative it was. Participants were asked to fill out a second CHABA Scale.

Challenging Behaviour Training
The training on challenging behaviour covered principles of behaviour management, focusing on strategies and assumptions of the nonaversive approach. Although within a
behavioural tradition, an emphasis was placed on an understanding of the service user's challenging behaviour in terms of learning history, social context and motivation. The training examined:

1) Definitions of challenging behaviour (aggression, self injury, stereotyped behaviour, passivity and anti social behaviour)
2) How to describe behaviour, using an example of a client known to service users
3) An examination of triggers and setting conditions which lead to certain behaviours (including avoid and escape, attention, tangible and sensation triggers; genetic, medication, bereavement and loss, abuse, environmental, physical and mental health setting conditions).
4) Interventions with challenging behaviour: changing setting conditions (practical exercise), positive programming (practical exercise), direct treatment and situational management.

Results

Participants

Of the 21 staff members attending the training events, 14 returned both pre and post questionnaires (response rate of 61.9%). However, one of the respondents did not identify him/herself on the post-training questionnaire, so the author was unable to include this participant in the evaluation. A further 7 participants returned only the pre training measure, and therefore were not included in the evaluation. This exclusion may have led to bias in the results, and will be discussed later in the report.

The demographic characteristics of the sample are summarised in Table 1.

It can be seen that the majority of the participants who responded were female, and were care assistants or support workers. Most of the participants had received none or very little training in challenging behaviour.
Differences between the respondents and non-respondents were explored (using Chi square analysis for sex, job title, qualifications, training and independent sample t-tests for age, months in current service and months working in learning disabilities). The respondents were significantly older than the non-respondents (p= <0.05) but no other statistically significant differences were found between the two groups.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>N (%) Respondents</th>
<th>N (%) Non Respondents</th>
<th>N (%) Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>N=13</strong></td>
<td><strong>N=8</strong></td>
<td><strong>N=21</strong></td>
<td></td>
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<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
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<tr>
<td>Male</td>
<td>4 (30.8)</td>
<td>3 (37.5)</td>
<td>7 (33.3)</td>
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<tr>
<td>Female</td>
<td>9 (69.2)</td>
<td>5 (62.5)</td>
<td>14 (66.7)</td>
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<tr>
<td><strong>Qualifications</strong></td>
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<tr>
<td>None</td>
<td>5 (38.5)</td>
<td>3 (37.5)</td>
<td>8 (38.1)</td>
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<td>NVQ</td>
<td>5 (38.5)</td>
<td>1 (12.5)</td>
<td>6 (28.6)</td>
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<td>Nursing</td>
<td>2 (15.3)</td>
<td>1 (12.5)</td>
<td>3 (14.3)</td>
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<td>Degree</td>
<td>1 (7.7)</td>
<td>3 (37.5)</td>
<td>4 (19.0)</td>
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<tr>
<td><strong>Job Title</strong></td>
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<tr>
<td>Support worker/care assistant</td>
<td>11 (84.7)</td>
<td>7 (87.5)</td>
<td>18 (85.7)</td>
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<tr>
<td>Home/service manager</td>
<td>2 (15.3)</td>
<td>1 (12.5)</td>
<td>3 (14.3)</td>
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<tr>
<td><strong>Training in challenging behaviour</strong></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>No training</td>
<td>5 (38.5)</td>
<td>3 (37.5)</td>
<td>8 (38.1)</td>
</tr>
<tr>
<td>One or two short courses</td>
<td>6 (46.1)</td>
<td>4 (50)</td>
<td>10 (47.6)</td>
</tr>
<tr>
<td>Several courses</td>
<td>1(7.7)</td>
<td>0 (0)</td>
<td>1 (4.8)</td>
</tr>
<tr>
<td>Extensive training</td>
<td>1(7.7)</td>
<td>1 (12.5)</td>
<td>2 (9.5)</td>
</tr>
<tr>
<td><strong>Mean (SD)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age in years</td>
<td>39.15 (10.87)</td>
<td>28.58 (4.59)</td>
<td>35.45 (10.39)</td>
</tr>
<tr>
<td>Months in current service</td>
<td>45.62 (61.31)</td>
<td>16.06 (9.91)</td>
<td>34.36 (50.06)</td>
</tr>
<tr>
<td>Months working in learning</td>
<td>103.39 (96.71)</td>
<td>59.65 (44.72)</td>
<td>86.71 (82.38)</td>
</tr>
<tr>
<td><strong>Disabilities</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The Challenging Behaviour Attribution Scale

Emotional attributions scored highest before training (items such as "they cannot cope with high levels of stress), indicating that respondents believed emotional factors in the person to be the most likely cause of challenging behaviour. The lowest scoring subscale was stimulation (items such as "They are bored") indicating that the respondents felt that this was the least plausible attribution for challenging behaviour. After the training, the highest subscale was still emotional, and the lowest still was stimulation. Although stimulation consistently scored lowest, the score was still a positive number, meaning that respondents felt it was a possible explanation, rather than a negative number meaning that they felt it was unlikely to be a cause of challenging behaviour.

The Wilcoxon Signed Ranks Test for matched pairs was used to compare the scores before and after training. This test was selected as the data provided by the CHABA is ordinal data thus ruling out a parametric test. There were no statistically significant differences between the pre and post training subscale scores. The mean scores on each subscale for both pre and post test are given in Table 2.

Table 2. Staff mean scores for the Challenging Behaviour Attributions Scale sub-scales before and after training

<table>
<thead>
<tr>
<th>Sub-scale</th>
<th>Before Training</th>
<th>After Training</th>
<th>Z</th>
<th>Test statistic</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Median Mean (SD)</td>
<td>Median Mean (SD)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Biomedical</td>
<td>1.0</td>
<td>1.26 (0.59)</td>
<td>1.17</td>
<td>1.14 (0.75)</td>
<td>-0.358</td>
</tr>
<tr>
<td>Physical environment</td>
<td>1.12</td>
<td>1.15 (0.69)</td>
<td>1.00</td>
<td>1.05 (0.98)</td>
<td>-0.489</td>
</tr>
<tr>
<td>Learned behaviour</td>
<td>1.50</td>
<td>1.31 (0.68)</td>
<td>1.67</td>
<td>1.19 (0.91)</td>
<td>-0.878</td>
</tr>
<tr>
<td>Stimulation</td>
<td>0.67</td>
<td>0.91 (0.92)</td>
<td>1.33</td>
<td>1.03 (0.99)</td>
<td>-0.624</td>
</tr>
<tr>
<td>Emotional</td>
<td>1.43</td>
<td>1.38 (0.58)</td>
<td>1.43</td>
<td>1.26 (0.75)</td>
<td>-0.255</td>
</tr>
</tbody>
</table>
Research dossier: Service Related Research

Satisfaction with training
Participants were asked to rate on a 5-point scale, how interesting they found the training (where 1 represented "not interesting" and 5 "very interesting"). 92.3% of participants rated the training as interesting or very interesting (eleven selected 5, one participant selected 4, and 1 participant selected 3). 12 (92.3 %) participants considered the training was aimed at the right level, whereas one participant felt that the training was "too easy". All 13 participants considered the training to be relevant (11 rated "very relevant", 1 rated "fairly relevant").

What was liked most about the training?
More than half the participants thought that the aspect of the training they liked most was that it related to clients that staff worked with, taking examples from their own experience.
A few participants mentioned the informal "friendly" atmosphere and pace of teaching.
Two people identified the involvement of the staff in small group exercises.

What was least liked about training?
Most of the participants identified lack of time as the least liked aspect of the training. Comments such as "too much crammed in" and "more time to cover issues" were common. Two participants identified the "wording" of the training, perhaps referring to jargon. One participant reported that "some of the ideas felt patronising", and a further respondent wrote, "I felt much of the training session contents I had already learnt through studying".

What changes would be made
The changes that participants would have liked involved either longer sessions (the group who had four short sessions) or extra sessions to cover the material (those who attended the one day training). No issues about the content of the training were suggested.
Training needs

Participants were asked to identify any topics which they would like training in. The most frequently mentioned needs were managing aggression and gentle teaching strategies (both mentioned by two participants) followed by positive programming, practical applications of challenging behaviour course, independent living skills, Makaton and manual handling (each mentioned by one participant).

Discussion

The participants appeared to evaluate the training in a favourable light, expressing satisfaction with the relevance of the material covered and the level that it was aimed at. Most participants would have liked more time devoted to training.

The hypothesised changes as measured by the CHABA were not found. It was hypothesised that after training, staff would begin to examine causal explanations relating to positive and negative reinforcement (the learned behaviour subscale), and environment contingencies (physical environment subscale) and reductions in attributions concerning biomedical explanations may be expected (biomedical subscale). However, none of these changes were observed. The biomedical subscale was the highest scoring scale before and after training, and higher than found in previous research (Hastings (1997) sample of 90 care staff reported a mean of 0.90 for the biomedical scale). The learned behaviour and physical environment scales did not show significant increases. A possible explanation for this is that both scales scored highly before training (1.31 for learned behaviour and 1.15 for physical environment) and there was little room for increase. In Hastings’ (1997) sample of 90 learning disability staff, the mean score for the learned behaviour scale was 0.53, and 0.08 for physical environment. The scores for each subscale were higher than reported elsewhere (e.g. Hastings, 1997), and may indicate respondents' uncertainty completing the questionnaire, or efforts to try and score the "correct answer" by indicating that all of the causal factors are relevant.
Post training questionnaires were given to the participants at the end of the training session. Changes may have occurred within the staff group over a longer period of time, given time to reflect on the training and to try out approaches discussed in the training sessions. Furthermore, qualitative feedback from the participants who received training in four separate sessions, suggested that they valued the time-scale as it enabled them to put into practice ideas from the sessions, and discuss problems at the next session. Feedback from the facilitators indicated this group participated more in discussion about the issues and application to service users. Unfortunately this group of staff returned fewer questionnaires (only 4 participants from this staff group returned both questionnaires). If a higher rate of response for this group had been achieved, it may have been useful to examine the results of each training event separately.

There are, however, some methodological flaws that must be considered as possible sources of bias in the research. Firstly, eight participants were excluded from the study as they did not complete the measures after training. The participants who did not complete the post training questionnaires mainly attended the four session design, rather than the whole day. Participants who were dissatisfied with training may be less inclined to return the questionnaires in the first instance.

Second, the CHABA questionnaires were given on two occasions, approximately 2-6 weeks apart. The CHABA is a fairly new questionnaire with only preliminary psychometric data available, and little is known to date about its stability over time. Participants, moreover, may have discussed the questionnaire with other staff members, thus influencing their responses. Merely having time to think about challenging behaviour, without experiencing the training, could have led to changes in scoring on the CHABA (maturational effects). However, in this study response changed little over time.

There was an absence of any measure that assessed the participants’ knowledge about challenging behaviour or skills working with people who display such behaviour. An
assessment of this kind could have assessed increase in knowledge or skill as a result of attendance at the training event.

The implications for the service
The training was regarded positively by those taking part. Most participants would have liked a longer training session to cover the material presented. This could be addressed by covering less material, but in more detail, or perhaps providing a follow up session where questions could be answered about the material covered. Most participants requested further training, some of which had been inspired by the training event (e.g. positive programming, gentle teaching strategies).

Further evaluation of the two different formats of the training events would be useful in establishing whether different formats produced change in attributions, and whether feedback from the participants was more positive for a particular format.

Conclusions
Those attending the challenging behaviour training reported that the training was interesting, relevant and aimed at an appropriate level. However, only 61.9% of participants returned both sets of questionnaires.

No statistically significant changes in causal attributions about challenging behaviour were detected, as measured by the CHABA. Further evaluation is necessary to determine whether attributions change over a longer time span, and whether changes in attribution lead to changes in staff behaviour.

The results of the evaluation have been fed back to the service in a presentation held on the 23.10.98.
References


13th August 1998

Dear staff member,

The learning disability service is currently evaluating the staff training on challenging behaviour. As part of this evaluation, we are asking staff to complete questionnaires about the training and their perceptions of challenging behaviour.

We are asking staff members to complete a questionnaire on three occasions, one questionnaire before the training starts, another questionnaire at the end of the training, and a further questionnaire about 3-4 weeks after the training has finished.

Please can you complete the enclosed questionnaire. The completed questionnaires will only be viewed by myself, not by the psychologist running the session. I will collect the questionnaires before the start of the training session.

If you have any questions about the evaluation, or require any further information you can contact me at

Thank you for your help with the evaluation,

Yours faithfully,

Carolyn Graham

Clinical Psychologist in Training
Appendix Two: Challenging Behaviour Attributions Scale

Consider how likely it is that the following statements are reasons for people/children with intellectual disabilities/learning disabilities engaging in challenging behaviours (see above for definition). Simply think generally about the most likely reasons for people with intellectual disabilities/learning disabilities behaving in this way.

Please give your response to each of the possible reasons, and use the scales below each reason to indicate your opinion. The key shows what the points on the scales mean.

VUL = Very Unlikely
UL = Unlikely
E = Equally Likely/Unlikely
L = Likely
VL = Very Likely

Please indicate your response by placing a circle around the appropriate point on the scale.

People/children with intellectual/learning disabilities engage in challenging behaviours
BECAUSE...

1. They are given things to do that are too difficult for them
   VUL  UL  E  L  VL

2. They are physically ill
   VUL  UL  E  L  VL

3. They do not like bright lights
   VUL  UL  E  L  VL

4. They are tired
   VUL  UL  E  L  VL

5. They cannot cope with high levels of stress
   VUL  UL  E  L  VL

6. Their house/classroom is too crowded with people
   VUL  UL  E  L  VL

7. They are bored
   VUL  UL  E  L  VL

8. Of the medication that they are given
   VUL  UL  E  L  VL

9. They are unhappy
   VUL  UL  E  L  VL

10. They have not got something that they wanted
    VUL  UL  E  L  VL

11. They live in unpleasant surroundings
    VUL  UL  E  L  VL

12. They enjoy it
    VUL  UL  E  L  VL

13. They are in a bad mood
    VUL  UL  E  L  VL

14. High humidity makes them uncomfortable
    VUL  UL  E  L  VL

15. They are worried about something
    VUL  UL  E  L  VL

Dr Richard Hastings 1997
Challenging Behaviour Attributions Scale

16. Of some biological process in their body
17. Their surroundings are too warm/cold
18. They want something
19. They are angry
20. There is nothing else for them to do
21. They live in a noisy place
22. They feel let down by somebody
23. They are physically disabled
24. There is not very much space in their house/classroom to move around in
25. They get left on their own
26. They are hungry or thirsty
27. They are frightened
28. Somebody they dislike is nearby
29. People do not talk to them very much
30. They want to avoid uninteresting tasks
31. They do not go outdoors very much
32. They are rarely given activities to do
33. They want attention from other people

Dr Richard Hastings 1997
Appendix three: Definition of Challenging Behaviour

Challenging behaviour has been defined as:

"Culturally abnormal behaviour(s) of such an 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 use of, or result in the person being denied access to, ordinary community facilities" (Emerson, 1995)

Examples of challenging behaviour include aggression to others, self injury and stereotyped behaviour.
### CHALLENGING BEHAVIOUR - STAFF TRAINING

<table>
<thead>
<tr>
<th>Name</th>
<th>Workplace</th>
</tr>
</thead>
</table>

**Part A: The training session**

1) **How interesting was the training? (please circle number)**

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Not interesting</td>
<td>Fairly interesting</td>
<td>Very interesting</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2) **Was the training aimed at the right level? (please circle number)**

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No - too easy or too hard</td>
<td>OK</td>
<td>at the right level</td>
<td>Yes</td>
<td></td>
</tr>
</tbody>
</table>

3) **How relevant was the training to your work? (please circle number)**

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>not at all relevant</td>
<td>fairly relevant</td>
<td>very relevant</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
4) What did you like most about the training?

5) What did you like least about the training?

6) What changes would you make to the training?

7) What other training have you received? (please list)

8) What other training is available to you?

9) What would you like more training in?

10) Please add any further comments about the training
"Psychological adjustment in survivors of breast cancer: a review of the literature."

Literature Review

Year III

October 1999
In the United Kingdom, breast cancer was the third most common cancer related death in 1995. It currently affects one in eleven women, with over 33,000 women diagnosed with the disease each year (Cancer Research Campaign, 1999). As new and more effective treatments are being developed to treat cancer, there has been an increasing number of women surviving far beyond treatment (Mahon and Casperson, 1997). No statistics are currently available to indicate how many of these women will go on to experience one or more recurrences of cancer, however remission rates of 20 years have been documented (Smyth, McCaughen & Harrison, 1995). Given the length of time that this cancer can be in remission, it is important to consider the long-term effects of surviving cancer upon individuals. Glanz and Lerman (1992) argue that a developmental perspective is useful in understanding breast cancer as the effects of diagnosis, treatment and course of the disease unfold over a long period of time and different psychosocial responses are evident at various points in the adjustment process.

**Survivorship**

A survivor has traditionally been defined as one who has been disease free for a period of 5 years or more. However Mullen (1985) asserts that the process of surviving begins at the time of cancer diagnosis. Lifton (1980, cited by Breaden, 1997) defined a survivor as one who "has touched, witnessed, encountered, or been immersed in death in a literal or symbolic way and has himself/herself remained alive" (Lifton, 1980, p.54). Although cancer survivors share many of the same experiences as those who survive disasters (e.g. recurrent nightmares and the loss of a sense of invulnerability), they are different from other survivors as they continue to deal with fears of recurrence of cancer (Breaden, 1997). Cella and Tross (1986) referred to this fear of recurrence as "Damocles syndrome", drawing a parallel between the legend of the sword of Damocles. In the legend, Damocles is invited to a banquet and seated under a sword hung by a single hair, so as to point out to him the precariousness of his position. The sword of Damocles represents the idea of imminent danger. Fallowfield and Clark (1991) write that fear of recurrence is an important issue for most women, as they face a large degree of uncertainty about their future being neither clearly ill nor clearly healthy. Fallowfield, Baum and Maguire (1987) found that 10 per cent of their sample of women with breast cancer reported at least daily breast self examination, indicating high levels of anxiety that exist about recurrence.
Most research has concentrated on the issues of long term survival, with little attention to those women embarking on the survival process (Breaden, 1997). Psychological aspects of survival include depression, anxiety, anger and feelings of shame (Taylor, Lichtman and Wood, 1984). Ferrell, Grant, Funk, Otis-Green and Garcia (1998a) surveyed a large number of breast cancer survivors (298) and found that psychological burdens related to the fear of breast recurrence were evident. A particular fear that was common in the respondents concerned anxiety over the risk of breast cancer in other female relatives. Concerns about future uncertainty, appearance and self concept, fear of a second or recurrent cancer and metastasis and distress from surgery were components affecting breast cancer survivors’ quality of life (Ferrell, Grant, Funk, Otis-Green and Garcia, 1998b).

**Mental health and breast cancer**

Psychological adjustment after a diagnosis of breast cancer has been the subject of much research and there is a consensus that women will experiences mental health problems during the period of diagnosis and treatment (Osowiecki and Compas, 1998). Various estimates of the prevalence of mental health problems in this group of women have been cited. For example, Watson, Greer, Rowden, Gorman, Robertson, Bliss and Tunmore (1991) examined levels of anxiety and depression using the Hospital Anxiety and Depression scale (Zigmond and Snaith, 1983) in 359 women. They were surveyed approximately one to three months after the diagnosis of breast cancer. Sixteen percent of women were classified in the clinical range for anxiety and six percent in the clinical range for depression. A greater proportion of women were identified as having a psychiatric disorder by Kissane, Clarke, Ikin, Bloch, Smith, Vitetta and McKenzie (1998). In total, just over three hundred women with early stage breast cancer were surveyed. Using a diagnostic interview schedule they found that 45% of women had a psychiatric disorder (42% of the sample had depression or anxiety or both, minor depression in 9.6% and phobic disorder in 6.9%).

There is some evidence to suggest that mental health problems continue during the first year after initial diagnosis. Vinokur, Threatt, Vinokur-Kaplan and Satariano (1990) studied 274 women at approximately four and ten months after diagnosis, finding significant improvements in physical functioning, but no improvement in mental health and well-being. Furthermore, those younger women with more serious impairments in
functioning experienced significantly bigger deterioration in mental health than similarly impaired older patients.

Women with recurrent or metastatic cancer have also been researched, although not as extensively. Fulton (1998) looked at the prevalence of psychiatric morbidity in a group of 80 women newly diagnosed with metastatic breast cancer. Measures were taken every eight weeks, for a period of 16 months. At the point of diagnosis, 39% scored in the clinical range for anxiety and 31% for depression. Although there was no statistically significant differences between the mean anxiety and depression score at any of the intervals, the author noted that the trend was for both scores to decrease over time. In a separate study, Fulton (1997) examined the levels of anxiety and depression 1-7 weeks before death in a sample of 44 women with metastatic breast cancer. Over half of the women scored in the clinical range for anxiety (66%) and depression (50%) on the HADS. These studies indicate that a high proportion of women with metastatic cancer experience significant mental health problems in the period after diagnosis and during the last few weeks of life.

**Mental health and breast cancer survival**

In contrast to the study of women at the time of diagnosis, relatively little work has focused on the period after the initial diagnosis or treatment. Ganz, Rowland, Meyerowitz and Desmond (1988) surveyed over a thousand women who had been diagnosed with early stage breast cancer between 1 and 5 years earlier, recruited from two large metropolitan centres in the USA. They asked women to complete postal questionnaires examining levels of depression, along with other factors. They found that the depression score approximated scores from the normal population of healthy women. They concluded that overall, breast cancer survivors function at a high level, similar to healthy women without cancer. This study did not however, include a standardised measure of anxiety. Anxiety has been consistently shown to be more prevalent than depression in studies examining mental health of women with cancer (e.g. Watson et al, 1991, Fulton, 1997, 1998). This survey may therefore have underestimated levels of psychological distress by the exclusion of a common mental health problem.

Saleeba, Weitzner and Meyers (1996) compared the mood of breast cancer survivors (n=52) five years and after the initial diagnosis, with breast cancer screening patients...
Questionnaire measures of depression and anxiety were utilised. The mean length of time since diagnosis was 8.5 years with a range from 5-18 years. The scores on both questionnaires were considerably higher for the breast cancer survivors than for the control sample. However, the mean depression score was within normal limits, and the mean anxiety score indicated a mild level. A higher percentage of women in the breast cancer group were in the mildly or moderately depressed groups (25% and 4% respectively) than those in the control group (mildly depressed 13% and moderately depressed 2%). On the anxiety scale 21% of breast cancer survivors scored in the mild to moderate ranges of anxiety compared to only 7% of the control group. 27% of the breast cancer group compared with 15% of the control group had elevated scores on the anxiety scale. The results suggest that long-term survivors of breast cancer continue to experience mild levels of anxiety and depression, five years and longer after initial diagnosis. However, this study eliminated women who had a previous psychiatric history from taking part. If these women were included in the study, possible higher prevalence rates would be identified.

Ellman and Thomas (1995) measured anxiety and depression in long term survivors of breast cancer, using the HADS. They compared 331 women with breast cancer with 584 controls who had attended a screening clinic but did not have breast cancer. In contrast to the findings of Saleeba et al (1996) significantly fewer symptoms of anxiety and depression were reported by patients with cancer than the screening control group. Furthermore, significantly fewer of the women surviving cancer had high scores indicating psychological morbidity. They concluded that the prevalence of anxiety and depression is not increased in long term survivors of breast cancer who are apparently free from disease. All measures in this study were obtained at the time of screening for possible cancer. Previous research has shown this to be an anxiety provoking procedure, with high levels of anxiety observed. As women treated for breast cancer are usually required to attend for follow up appointments, during which mammograms may be performed. It is therefore possible that due to regular, routine follow up appointments these women are more likely to have habituated to these appointments, so respond with less anxiety than those for who it is a novel situation. Alternatively, it is also plausible that anxiety may become more pronounced with repeated follow up visits.
Dow, Ferrell, Leigh, Ly, & Gulasekaram (1996) surveyed 294 breast cancer survivors, belonging to a cancer survivors' organisation. They concluded that psychological distress from cancer diagnosis and treatment, and fear of recurrent cancer and metastatic disease were problematic over time and that uncertainty over the future concerned breast cancer survivors. It must be pointed out that there is a possible sample bias in this study, as they focused exclusively on members belonging to a survivors' organisation whose membership may be unrepresentative of the larger group of women surviving breast cancer.

Two studies to date have investigated posttraumatic stress disorder (PTSD) in breast cancer survivors. According to DSM-IV (American Psychiatric Association, 1994) traumatic events that may precipitate PTSD, include being diagnosed with a life-threatening illness. Andrykowski, Cordova, Studts and Miller (1998) report the prevalence of posttraumatic stress disorder in women 6 to 72 months after the diagnosis of breast cancer. 82 women were interviewed, using both a self-completion questionnaire and a structured diagnostic interview for PTSD based on DSM-IV (American Psychiatric Association, 1994). A diagnosis of current PTSD is given to those women who currently meet the criteria for PTSD, and a diagnosis of lifetime PTSD is given to those women who have met the criteria in the past. They found a prevalence rate of 6% and 4% of current and lifetime PTSD respectively. They concluded that PTSD can be precipitated by diagnosis and treatment of breast cancer. Furthermore, they speculate that the prevalence identified by this study might reflect an underestimate of PTSD due to a sample bias. The individuals who chose not to participate were less educated than the participants. Citing research by Cordova, Andrykowski, Kenady, McGrath, Sloan and Redd (1995) they claim that less education has been linked to greater reports of PTSD symptoms in breast cancer patients. They therefore estimate that a higher percentage of individual's with cancer might meet the criteria for a diagnosis of cancer related PTSD within 5 years of diagnosis. This, however, needs to be investigated further.

In summary, there is a mixed picture concerning levels of psychological distress in survivors of breast cancer. Some studies have shown levels of distress no different to that found in the general population and other studies have indicated higher levels of distress of a sub-clinical nature. Two studies have found evidence of breast cancer related PTSD, although their estimates of prevalence need further investigation.
There are a number of difficulties encountered when attempting to draw conclusions from the research literature. First, there are difficulties comparing studies in this area as they have typically been conducted with participants of different ages. Age has shown to be an important factor in adaptation to breast cancer (e.g. Vinokur et al, 1990), with younger women experiencing significantly more mental health problems than older women with similar levels of disability. Research has been subject to various biases, with samples being drawn from support organisations and private health care clinics. Common points for taking measures of psychological adjustment are during follow up appointments, which are often reported as times of high anxiety and stress. Furthermore, a variety of different assessment methods have been used to identify mental health problems, which may contribute to some of the differences identified in prevalence.

Further research is necessary to establish the levels of adjustment in survivors. As adjusting to breast cancer is a process, beginning with diagnosis and treatment, the issues affecting women during each phase of the process may well be different. Future research needs to address this, using representative samples. As age is known to influence adjustment, particular attention needs to be paid to this as a mediating factor, along with time since diagnosis and treatment.

**Illness cognitions and psychological adjustment**

One way of understanding why some women adapt well in response to a diagnosis of breast cancer, and remain well adjusted throughout the survival process is to examine theoretical explanations of coping with illness threats. Buick (1997) asserts that the individual differences in adjustment to cancer suggest that individuals hold different perceptions of the experience of having cancer which may implicate cognitive factors as a key issue shaping psychological response.

Leventhal, Meyer and Nerenz (1980) developed the self regulatory theory which has been used as a theoretical framework for understanding why some people experience psychological distress when dealing with a threat to health. The model describes and predicts how people respond to health related stressors (Kemp, Morley and Anderson, 1999). A key part of this model is illness representations or cognitions. These cognitions provide a schema framework for coping with and understanding illness. Therefore, an
Individual's cognitive representation of illness directs their efforts to cope. Within this model, psychological adjustment is the result of an ongoing process in which people integrate illness related information with existing cognitive structures to form an illness representation.

Four cognitive dimensions of beliefs were initially identified (Leventhal and Nerenz, 1985):

- **Identity** - the label given to the illness and beliefs about the symptoms and diagnosis
- **Perceived cause** - beliefs about the cause of the illness e.g. biological, psychosocial.
- **Time line** - the perceived duration of the illness e.g. acute vs. chronic.
- **Consequences** - the perceived impact of illness on life

A fifth dimension, control / cure was added by Lau and Hartman (1983), although there has been debate as to whether it is an attribute of illness representations, or it is a summary of the expected outcomes of coping (Leventhal and Nemez, 1985).

Within this model, the individual is seen as motivated to problem solve and re-establish their state of normality when dealing with a health threat (Ogden, 1996). A parallel response framework has been hypothesised with two mostly independent processing systems, with one creating the cognitive representations of illness and the other an emotional processing system which acts to initiate coping strategies and create emotional states (Leventhal, Diefenbach and Leventhal, 1992). Both processing systems are interactive, and may be affected by the self system (e.g. biological characteristics, psychological traits) and the socio-cultural context (e.g. institutions and rules).

Four stages of the self-regulatory model have been identified, interpretation, emotional response, coping response, appraisal and evaluation. For example, when a breast lump is detected it is assumed that the individual matches this symptom to pre-existing "illness prototypes" (Bishop & Converse, 1986). This symptom may fit within her "breast cancer" prototype and lead to the assumption that she has cancer. This in turn, may lead to anxiety as an emotional response. Suitable coping styles are adopted in an attempt to return to a state of normality (Ogden, 1996) and these coping styles are then evaluated and appraised and an alternative is selected if appropriate.
The model views illness related coping and adjustment as the result of an ongoing process (Kemp et al 1999). Psychological adaptation is thought to be mediated by the adoption of certain coping styles. Strategies such as self blame, emotional ventilation and cognitive and behavioural avoidance have been linked to difficulties in adjusting to disease, whilst positive reframing, acceptance, planning and utilising social support have shown inverse relationships with distress (Moss-Morris, Petrie and Weinman, 1996). In advanced cancer, coping styles entitled fighting spirit (an attitude of optimism in the face of a realistic appraisal of their illness) and emotional expressiveness have been found to be associated with better adjustment (Classen, Koopman, Angell and Spiegel, 1996).

However, recent research has implicated illness cognitions as possibly playing a direct role in psychological adjustment, and have explained greater variance in psychological distress than coping styles adopted. Schiaffino, Shawaryn & Blum (1998) examined illness representations and relationship to mood in people with rheumatoid arthritis. A multivariate analysis of variance was performed to examine the relationship between the participants illness cognitions and depression. The belief that the disease was curable and in ones own responsibility for it was related directly to levels of depression. Heijmans (1998) examined the role of coping and adaptive outcome in chronic fatigue using the illness cognition framework. She concluded that those participants who viewed their illness as a serious condition, believed that it was uncontrollable with no prospect for cure and saw their illness to have serious consequences, coped with their illness in a passive way, and reported impairments in social and psychological functioning. It was found through a series of regression analysis, that illness representations were stronger predictors of adaptive outcome than coping scores, with the identity component showing the strongest predictive ability. Moss-Morris, Petrie and Weinman (1996) also examined illness perceptions in chronic fatigue syndrome. They sent postal questionnaire measures of illness representations, coping, disability levels and psychological well being to members of chronic fatigue organisation. 233 members returned the questionnaire representing a response rate of around 50%. The components of identity, emotional causes of illness, controllability/curability and consequences has the strongest overall association with measures of functioning. The authors suggested that individuals who had the highest number of symptoms, believed their illness was out of control, caused by stress and had serious consequences, showed low levels of psychological adjustment and higher levels of dysfunction.
Illness perceptions and cancer

Nerenz, Leventhal, Love and Ringler (1984) examined coping with chemotherapy and the role of illness perceptions. They studied patients with malignant lymphoma, who appeared to determine the effectiveness of chemotherapy by monitoring the size of the diseased lymph nodes. Those people who experienced a sudden disappearance of the nodes as a result of the chemotherapy were much more distressed than those whose tumour gradually reduced. A possible explanation for the heightened distress of those with rapidly shrinking tumours, were that these patients no longer had an observable method of assessing the effectiveness of treatment. An alternative explanation is that the patients saw the rapid shrinking of the tumour as a cure of their cancer and they consequently did not understand having to continue treatment despite being cured. This research suggests that individuals had an implicit model of illness (Turk, Rudy and Salovey, 1986), in which symptoms act to define the presence or absence of disease and mediate patients’ psychological response.

Osowiecki and Compas (1998) examined the role of control beliefs, coping and adjustment in adult cancer patients. 83 patients were interviewed approximately 10 weeks after their diagnosis. 82% of the sample were women, and included people with various types of cancer including malignant melanoma, breast, gynaecological, testicular and lung cancer. They asked patients to rate whether they used emotion or problem focused coping, and evidence was found that both coping strategies were related to emotional distress. Regression analysis revealed that problem focused coping was related to less psychological distress and the reverse was true for emotion focused coping. The kinds of emotion focused coping that were typically reported by the participants were denial and avoidant types of coping, whereas examples given of problem focused coping involved seeking information about cancer and following treatment recommendations. The combination of high perceptions of personal control and the use of more problem focused coping was associated with lower levels of anxiety and depression in the sample. The authors conclude that active, problem focused coping may be associated with lower distress for those people who believe they have a degree of control over their cancer. This research shows the importance of both cognitive representations of cancer (control/cure) and coping styles in mediating psychological adaptation.
There are several issues to consider when interpreting the results from this study. The sample size was relatively small, and included people with various forms of cancer. As treatment for each type of cancer is likely to take different forms, and the prognosis may well be different, the validity of treating this group as a cohesive group of "cancer patients" is questionable. Caution must be exercised when drawing conclusions from this piece of work as people with different types of cancer may well adapt to the diagnosis and treatment in a number of ways considering the differences in treatment and outcome. Nonetheless, one of the findings of the study was recently confirmed by Chen, David, Thompson, Smith, Lea and Fahy (1996). They studied women attending breast screening clinics, and found that women who actively confronted their illness and the uncertainty around it showed better psychological adjustment.

Taylor, Lichtman and Wood (1984) examined causal attributions and beliefs about control (consistent with the concept of causality and controllability in the self regulatory model). Attribution theory predicts that when a stressful event is encountered, a search for the cause will begin in an effort to understand the reasons for the threat (Taylor et al, 1984). According to this theory, attributions are made in an effort to understand, predict and control the threat. They hypothesised that causal attributions may be especially useful early on in the adjustment process, at around the time of diagnosis, when women have to process the threat of cancer. Furthermore, they predicted that women who believed that they could exert some level of control over the cancer would show better psychological adjustment than those who did not. 179 patients of a private cancer practice were approached to participate in the study. A response rate of 49% was achieved. The respondents were skewed towards the middle and upper socio-economic classes, with a disproportionate Jewish representation (31%). Women with various stages of breast cancer were recruited for the study, 38% had stage 1 breast cancer, 45% had stage 2 breast cancer, and 18% had distant sites of metastases. The range of time since surgery was 1-60 months. Ninety five percent of the sample had made causal attributions about their breast cancer. The sample were asked retrospectively about the period when causal attributions were most important. Only 28% of the sample felt that it was important at diagnosis, whilst 41% indicated that it was important during recovery and 41% said that the issue was important to them at the current time. The authors point out the need to be cautious when examining this issue as the women were being asked to make retrospective ratings. Nonetheless, the prediction that causal attributions were most useful at the time
of diagnosis was not supported by this data. Attributions of responsibility to the self, environment and chance showed no relationship with positive psychological adjustment. Blaming another person for the onset of cancer was correlated with poorer adjustment. The authors assert that the blame of another may be indicative of unresolved anger and distress. In this study, the anger appeared to be aimed either at the medical profession for not diagnosing the cancer at the right time, or for not giving the right treatment at the appropriate time, or to the spouse or ex-spouse for creating the stress which they perceived to cause the cancer. Beliefs about control of the cancer also were shown to be important predictors of psychological adjustment. The beliefs in one's own control and in others control were both independently associated with better adjustment. The authors suggest that the understanding and predictability usually created by attributions during a stressful event may be provided by cognitions other than causal attributes.

There are however, some methodological flaws with this design. Firstly, the large proportion of women from middle or upper socio-economic classes may make it difficult to generalise these findings to other population. The authors suggest that women from lower socio-economic groups may have different priorities and may be less concerned with causality but more concerned with practicalities such as the financial implications of cancer. Furthermore, the disproportionate number of women from the Jewish faith may also lead to problems generalising this research to other women. Farmer and Good (1991) assert that illness representations are dimensions of culture, and that cultures vary as to how their symptoms are interpreted, how bodily sensations or illness labels are evaluated and given meaning.

Buick (1997) has conducted one of the few studies examining the role of illness perceptions in adjustment to breast cancer. She asserts that an individual’s causal beliefs may influence psychological adjustment to cancer. In her comparison study of women undergoing either chemotherapy or radiotherapy for breast cancer, she hypothesised that attitudes have an impact on patients perceived vulnerability to a recurrence of cancer. With reference to cognitions comprising the causal dimension of illness representations, she found that women’s attributions of causality changed during and following treatment. For example, attributions made to chance happenings or genetic causality strengthened during and following treatment. She argues that this may represent an attempt to restructure illness perceptions in preparation for a period of uncertainty, when the
likelihood of recurrence is a realistic expectation. The attribution changed towards chance and genetics suggesting an attempt by the individual to establish causality that was not due to personal responsibility. She argued that this attribution may be especially important for development of patients perceived vulnerability to recurrence following active medical interventions.

Furthermore, she found that chemotherapy and radiotherapy patients had different beliefs about the cause of breast cancer. Those women undergoing chemotherapy were more likely to report internal, self-blame and environmental attributes as opposed to radiation patients who reported a greater belief in chance. A possible reason for the differing beliefs across treatment types is the notion of severity. Chemotherapy generally lasts longer than radiotherapy (6 months compared with 4-5 weeks, Buick, 1997), and as such may be perceived by the women as a marker of disease severity. Indeed, before commencing chemotherapy, women receiving this treatment perceived that their breast cancer would last a long time and have greater impact on their lives than the women who were due to receive radiation therapy. Buick asserts that women receiving radiotherapy may compare themselves with women having chemotherapy and believe they are better off. This is a similar concept to the secondary victimisation concept as described by Taylor, Wood and Lichtman (1983), who found that nearly all women (over 97%) with breast cancer that they interviewed believed that were doing as well or better than other women coping with the same situation. They found that women were making downward comparisons with other women receiving treatment for cancer (e.g. a lumpectomy patient comparing herself with a woman who had a mastectomy, an older woman comparing herself with a younger woman or a married woman comparing herself with a single woman).

Buick (1997) concludes that women’s illness perceptions form a primary component of the cognitive interpretative framework within which "cancer experience is defined and made sense of" (Buick, 1997). She argues that illness perceptions therefore, become important as mediating factors shaping psychological and behavioural responses to cancer treatment. If this conclusion was extended, illness cognitions could be implicated in mediating psychological responses to surviving breast cancer.
Summary
To conclude, studies to date have identified different levels of psychological distress in women surviving breast cancer. Buick (1997) writes that the current literature indicates a wide array of psychological response to cancer diagnosis, surgery and survival. A theory that may be able to explain differing levels of psychological distress, is the self regulatory model.

Research has begun to examine the role of illness cognitions and its effect on psychological adjustment in a variety of disease conditions. However, few studies have examined illness cognitions in women with breast cancer, and no work to date has explicitly applied this framework to those beyond the initial diagnosis and treatment phase. This model offers a promising framework for the development of understanding psychological adjustment to surviving breast cancer.

References


Major Research Project: Anxiety and Depression in Breast Cancer Survivors: The Role of Illness Perceptions

Year III

July 2000
Background. Research has demonstrated that illness perceptions are related to psychological adjustment in a variety of illness conditions. However, few studies have examined the role of illness perceptions in women surviving breast cancer. This study aims to explore the relationship between anxiety, depression and illness perceptions in women 18 months to five years post treatment for breast cancer.

Design. A cross-sectional survey utilising standardised questionnaires and in-depth interviews to collect data from participants.

Methods. 40 women were interviewed, 18 to 56 months after being diagnosed with breast cancer. Participants were asked to complete questionnaires assessing levels of anxiety, depression, illness perceptions and coping style. Semi-structured interviews were used to obtain information about the content of illness perceptions amongst this sample.

Results. Two illness perception components were found to be correlated with anxiety but not depression scores. A higher identity score (higher number of reported breast cancer related symptoms) was positively associated with anxiety and depression, and a belief in the serious consequences of breast cancer was associated with anxiety scores. No relationship between coping style and anxiety or depression scores was found.

Conclusions. The self-regulatory model predicts that coping mediates psychological adjustment. The results from this study indicate that illness perceptions may directly influence psychological adjustment and may be a better predictor of psychological adjustment than coping style. While findings from research in other illness conditions supports this conclusion, it is possible the reverse relationship holds, i.e. that psychological adjustment influences illness perceptions. Thus this conclusion must be regarded as tentative at this stage, with further research required concerning the direction of causation between illness perceptions and psychological adjustment.
Introduction

Breast cancer is the most common form of female cancer occurring in the United Kingdom, and was the third most common cancer related death in 1995. It currently affects one in eleven women, with over 33,000 women diagnosed with the disease each year (Cancer Research Campaign, 1999). A recent report examined all cancer patients diagnosed in England and Wales between 1971 and 1990 (Cancer Research Campaign, 1999). The report found that of those women diagnosed with breast cancer between 1986 and 1990, 66% survived for five years (figures age standardised), indicating a high survival rate compared to many other cancers. However, the 66% five year survival rate would include women who have a cancer recurrence during this time. Disease free remission periods of up to 20 years have been documented (Smyth, McCaughen and Harrison, 1995).

Therefore, as a result of new and more effective treatments developed to treat cancer, there has been an increasing number of women surviving far beyond treatment (Mahon and Casperson, 1997). These women, however, are living with the risk of disease recurrence at a later stage (Lee-Jones, Humphris, Dixon and Bebbington Hatcher, 1997). Therefore, it is essential to consider the long-term effects of surviving cancer upon individuals.

Polinsky (1994) contrasted the wealth of information and research about breast cancer patients with the little information that is available about survivors beyond the initial treatment phases. Polinsky wrote that "what begins as a crisis involving diagnosis and treatment gradually becomes a chronic illness characterized by lifelong medical care, indelible psychological effects, and changes in social and employment relationships". Rabinowitz (1997) described the assumption that is often made that women will be free of ongoing emotional difficulties once treatment has been completed. However, Taylor, Lichtman and Wood (1984) asserted that the psychological aspects of survival include depression, anxiety, anger and feelings of shame. The ability to identify and reduce any
psychological effects would be beneficial to survivors, however research is still in its infancy concerning issues facing those embarking on the survival process.

**Anxiety and depression in breast cancer survivors**

In contrast to the study of women at the time of cancer diagnosis, relatively little work has focused on the period after diagnosis and treatment. For a comprehensive review of the research concerning anxiety and depression in breast cancer survivors, see Graham (2000, p135-151 this dissertation).

Rabinowitz (1997) asserted that there is much variability in longer-term emotional consequences for women with breast cancer. Saleeba, Weitzner and Meyers (1996) investigated women five years or more after a breast cancer diagnosis and found that 25% of the sample scored in the mildly depressed range and 4% in the moderately depressed range. On an anxiety scale 21% of survivors scored in the mild to moderate ranges of anxiety, indicating significant levels of anxiety and depression of a mild to moderate nature.

In contrast, Ellman and Thomas (1995) compared survivors to a group of women attending a breast clinic for screening purposes. They found that the cancer survivors had lower levels of anxiety and depression than those women attending for screening. 21% and 6% of cancer survivors scored in the borderline range for anxiety and depression respectively, and 6% and 3% scored in the clinical range for anxiety and depression. Furthermore, they found that anxiety levels were higher in the first annual follow-up visit and less common in those attending for later visits.

In conclusion, there is a mixed picture concerning levels of psychological distress in survivors of breast cancer with some studies indicating levels of distress similar to that found in the general population whilst other studies have indicated higher levels of distress of a sub-clinical nature.

The mixed research picture could be accounted for by methodological problems apparent in many research studies. Research has been subject to various biases, with samples often taken from informal support organisations and private health care clinics. This could lead
to an under-representation of psychological adjustment problems, as those women who chose to belong to support groups may be functioning at a better level than those who do not become involved, or vice versa. Questionnaires are often completed during follow up appointments, for example during routine screening for recurrence (Ellman and Thomas, 1995), which are often reported as times of high anxiety and stress (Fredette, 1995). For a more comprehensive discussion of these methodological issues see Graham (2000, p141 this dissertation).

Hughes (1991) argued that the distress in cancer survivors is often unrecognised and concluded that there are several factors that may contribute to this. They include an under recognition of symptoms due to the difficulties of diagnosing anxiety and depression in physically ill individuals, and a common belief that because anxiety and depression in cancer are "understandable" they do not merit specific treatment.

Despite differing estimates of prevalence, it is important to examine theoretical explanations for psychological adjustment in the face of a life-threatening health condition. One theory that has been developed is the illness perception model which is thought to explain how individuals process and cope with threats to health and how this process impacts upon psychological well-being.

**Illness perceptions**

Illness perceptions have been defined as implicit, common sense beliefs about an illness (Leventhal, Meyer and Nerenz, 1980). Illness perceptions can be categorised according to five theoretical dimensions: *identity, time line, consequences, control/cure* and *cause*. The illness perceptions provide a schema for understanding and coping with illness. *Identity* concerns the labels that are given to the illness and the symptoms that are experienced (Ogden, 1996). *Time line* covers beliefs about the length of the disease or illness and is often divided into acute, cyclical and chronic models. Beliefs about control or cure relate to whether the disease can be controlled or cured and included perceptions about the role of personal control over the disease or illness. *Consequences* refers to the
perceived costs and benefits (if applicable) of the health threat, whereas \textit{Cause} relates to the perceived cause of the condition and may include physical, psychological and environmental factors.

Illness perceptions form part of the model of self-regulatory behaviour (Leventhal, Meyer and Nerenz, 1980). An individual is regarded as an active problem solver who is motivated to re-establish a state of normality when faced with an illness threat (Ogden, 1996). Leventhal, Diefenbach and Leventhal (1992) propose a two stage processing system, one to create illness perceptions and an emotional processing system which is thought to initiate coping strategies and subsequently influence emotional states. These systems are thought to be interactive, as emotional state can influence the processing of illness information (the induction of negative mood increases reporting of symptom severity (Croyle and Sande, 1988, cited by Leventhal, Benyamini, Brownlee, Diefenbach, Leventhal, Patrick-Miller and Robitaille, 1997).

This model can be used as a theoretical structure for understanding individual differences in adjustment to illness or disease. Illness perceptions are a key component of the process of adaptation to an illness, with psychological adaptation thought to be mediated by the adoption of specific coping styles.

The process model of coping (Folkman and Lazarus, 1985) defines two models of coping; problem and emotion focused coping. Problem focused coping refers to behavioural and cognitive strategies to deal with threats by changing the environmental conditions or one's own behaviour, whereas emotion focused coping refers to psychological strategies to regulate the emotional consequences of a stressful event through cognitive or behavioural efforts (Broadstock and Borland, 1998). Problem and emotion focused coping have been linked to illness perceptions.

Research in other illness conditions has found that illness perceptions explain a greater variance in psychological distress then the coping styles adopted. For example, Heijmans
(1998) found that illness perceptions were a stronger predictor of adaptive outcome than coping scores.

Buick (1997) concluded that the breast cancer research to date has ignored the possibility that illness perceptions could be predictors of psychological adjustment. Little research has explicitly used illness perceptions to guide investigations. Some studies however, have demonstrated links between anxiety, depression and illness perception components but have not considered how each component related to adjustment and how the components interacted with each other.

A summary of research findings concerning the relationship between illness perceptions and psychological adjustment will be presented, focusing on breast cancer research. The illness perceptions framework of identity, time line, consequences, control/cure and cause will be used.

**Identity**

The identity component concerns the symptoms of the illness (Moss-Morris et al, 1996). Although survivors by definition are in remission from cancer, they may continue to experience physical symptoms due to the medical interventions received. Therefore, in the case of breast cancer, a strong illness identity may include symptoms related to the surgery or treatment.

Once a diagnosis has been established, surgical intervention may be necessary, ranging from removal of the lump (lumpectomy) to mastectomy (total excision of breast). Surgical intervention can lead to enduring physical side-effects such as pain around the site of surgery, or phantom breast pain. Axillary lymph node dissection is often performed at the time of surgery. This involves the removal of lymph nodes in the armpit in order to determine prognosis. This can lead to long-term side effects, including pain, numbness, swelling of the arm (lymphedema) and stiffness in the arm and shoulder (Hack, Cohen, Katz, Robson and Goss, 1999). Knobf (1990, cited by Polinsky, 1994)
argues that for some women the axillary node dissection can cause more problematic side
effects than the breast cancer surgery itself.

Common treatments for breast cancer include adjuvant (treatment following surgery
given even when there are no symptoms of cancer) chemotherapy, radiotherapy and
hormone therapy (Buick, 1997). Radiotherapy is thought to target the cancer cells that
may remain after surgery and therefore reduce the risk of a recurrence. Chemotherapy
involves the administration of toxic chemicals to rapidly dividing cells. It is a systemic
treatment aimed at destroying cells that have metastasised in other areas of the body
(Buick, 1997). Chemotherapy and radiotherapy often causes unpleasant side effects
during the treatment period such as nausea, vomiting, hair loss, skin reaction, pain and
breathlessness but may also be responsible for longer lasting side effects (da Costa and
Armand, 1997). Berglund, Boland, Fornander, Rutqvist and Sjoden (1991) found both
chemotherapy and radiotherapy patients to have remitting problems with continuing
negative impact on the quality of life, 2-10 years after treatment. Decreased stamina was
reported by those who had received radiotherapy, whereas those patients who had
received chemotherapy reported lingering smell aversions.

Adjuvant hormonal therapies, such as tamoxifen, can also lead to physical symptoms.
Tamoxifen has been shown to prolong both disease free and overall survival
(Pritchard, 1997). The physical side effects associated with tamoxifen include an increase
in the risk of endometrial cancer, menopausal symptoms such as hot flushes in 10-20% of
postmenopausal and 60% of premenopausal women (Pritchard, 1997) and weight
problems (Ganz, Rowland, Meyerowitz and Desmond, 1998).

Therefore, even though cancer may be in remission there are often long-lasting symptoms
associated with the treatment of breast cancer. Polinsky (1994) surveyed over two
hundred survivors of breast cancer between 16 months and 32 years post diagnosis. The
chronic nature of the condition was illustrated by continued numbness, weakness in arms,
body image issues, pain, swelling and other physical effects of surgery.
Woods and Earp (1978) found a relationship between the extent of physical symptoms and a depression following mastectomy. Those women who reported more physical symptoms were also more likely to report a higher number of symptoms of depression. The link between identity and psychological adjustment has also been demonstrated in other conditions. For example, Moss-Morris, Petrie and Weinman (1996) examined illness perceptions in chronic fatigue syndrome and found that a stronger identity component was related to lower levels of psychological adjustment. This finding was replicated by Heijmans (1998) who found that the identity component had the strongest predictive ability of adaptive outcome in chronic fatigue syndrome.

Time line
The time line component concerns beliefs about how long the disease will last. This includes the concept of acute, cyclical and chronic conditions. Cancer is often considered to be a chronic illness (Leventhal et al, 1997), however the perceptions of individuals with cancer may often be different. For example, Leventhal, Easterling, Coons, Luchterhand and Love (1986 cited by Leventhal et al, 1987) studied a group of women with metastatic breast cancer. Metastasis is the appearance of a mass of cancer in another part of the body at a distance from the original cancer (Fallowfield and Clark, 1991). The authors found that 29% of the women regarded their condition as acute and curable during cycles of chemotherapy, but 6 months later only 11% viewed their condition as acute and curable. This illustrates both the differing perceptions of time line that individuals' may hold and how these beliefs can change over time or as a result of changes in other illness perceptions. Leventhal et al (1986) suggest that the change in the time line was influenced by a change in the perceptions of control, as six months of chemotherapy failed to produce complete remission.

Gutmann, Pollock, Schmidt and Dudek (1981, cited by Kemp, Morley and Anderson, 1999) interviewed patients recovering from cardiac bypass surgery at different points in their treatment. They found that patients held different time line beliefs for their condition including acute, cyclical and chronic. The individuals who held a chronic time
perspective saw themselves as ill and were generally more pessimistic (Kemp et al, 1999).

Consequences
Beliefs about consequences refers to the perceived effects of the breast cancer. As discussed earlier, many of the treatments for breast cancer can produce unpleasant side effects that endure for a significant period of time, and also can increase the risk of malignancies at other sites. Ganz et al (1998) surveyed over a thousand women survivors of breast cancer to investigate health related quality of life. The authors found that survivors who had received any form of adjuvant therapy had poorer scores on a physical functioning scale than those women who did not receive adjuvant therapy. Chemotherapy and radiotherapy can lead to physical symptoms throughout the typical treatment period of six months but may also be responsible for longer lasting side effects such as cardiac toxicity and secondary malignancies (da Costa and Armand, 1997).

In addition to the physical sequelae of breast cancer, there are also psychosocial effects to consider. Polinsky (1994) described breast cancer as a chronic condition with psychological effects and changes in social and employment relationships. Polinsky found that decreased feelings of sexual attractiveness were a common occurrence in her sample of cancer survivors belonging to a self-help organisation (reported by 57% of participants). Other reported effects included dissatisfaction with body changes caused by cancer, thinking about recurrence and anxiety concerning medical check-ups. Ferrell, Grant, Funk, Otis-Green and Garcia (1998) found that in a sample of nearly three hundred survivors, women generally reported positive social well being but described concern for other female relatives and family distress.

Control or Cure
The control/cure component of the illness perception model refers to beliefs about control and cure of the illness. With regards to breast cancer, it concerns beliefs about
how effective the treatment was in "curing" the cancer and whether the cancer is likely to reoccur or spread.

Osowiecki and Compas (1999) argued that some breast cancer patients experience high levels of perceived control whereas others perceive the cancer to be relatively uncontrollable. Taylor, Lichtman and Wood (1984) found that personal control beliefs predicted psychological adjustment to breast cancer. A strong belief in one’s own ability to control cancer was associated with better psychological adjustment as was the belief that others were able to control the cancer.

There has been limited research examining survivors’ views about the recurrence of breast cancer. For example, Ferrell, Grant, Funk, Otis-Green and Garcia (1998) surveyed a large number of breast cancer survivors (298) and found that psychological burdens related to the fear of cancer recurrence were evident. Concerns about an uncertain future and fear of a secondary or recurrent cancer/metastasis were components found to be affecting survivors’ quality of life.

Fallowfield, Baum and Maguire (1986) found that 10 % of their sample of women with breast cancer reported at least daily breast self examination which indicated the high levels of anxiety that existed about the possibility of recurrence.

Fear of recurrence is frequently described as a major concern of breast cancer survivors (Fredette, 1995). Women often report that minor physical discomfort is feared to be a sign that the disease has reoccurred. Rabinowitz (1997) argues that although this focus on physical symptoms diminishes over time, the anxiety and awareness is often reported as lifelong. This fear of future recurrence is often evident at the time of a medical follow up appointment. Wyatt, Kurtz and Liken (1993) interviewed mastectomy patients and found unresolved issues including concerns of whether the doctor was checking carefully enough and dreading check ups due to their personal fears of recurrence. Polinsky (1994)
surveyed women an average of eight years after diagnosis and found that women continued to express the fear of recurrence and anxiety concerning medical follow-up.

**Cause**

This component concerns the perceived cause of the breast cancer. Epidemiological evidence suggests that hormones play a major role in the etiology of the disease. Henderson and Feigelson (1997) discuss the known risk factors for breast cancer. They conclude that an early menarche, late menopause and estrogen replacement therapy, all of which are measures of cumulative exposure to estrogen and possibly progesterone, may be linked to the disease etiology. Genetic susceptibility may be responsible for breast cancer in approximately 5% of cases in North America, but may be responsible for 90% of breast and ovarian cancer within some families. Other possible risk factors include dietary factors (high fat intake) and alcohol consumption (Henderson and Fiegelson, 1997). Another possible risk factor that has been suggested is the Type-C behaviour pattern. Type C behaviour pattern consists of a coping style of passivity, cooperativeness and emotional non-expression (Temoshok and Dreher, 1991). Research examining this concept has focused on the relationship between coping styles and cancer survival rates. For example, Spiegel, Bloom, Kraemer and Gottheil (1989) randomly assigned 86 women with metastatic cancer into a weekly support meeting and a control condition of routine care. The support meeting facilitated the expression of affect (emotion-focused coping). The participants were followed up ten years later. Although the majority of the sample had died (N=82), the survival time for those receiving group therapy was 36.6 months compared to 18.9 months for those in the control group. However, as no biological link between emotional processes and cancer has been proven (Spiegel, 1991) no firm conclusions can be made about the role of behaviour patterns in the etiology of cancer.

Studies examining perceived *cause* for breast cancer have found that women often hold a variety of causal beliefs which often differ to the medical explanations. Taylor, Lichtman and Wood (1984) hypothesised that attributions made to factors under personal control
would be more adaptive than attributions made to uncontrollable factors, and that attributions that are less likely to be under personal control (e.g. blame of another person, environmental factors) would be related to poorer adjustment. They surveyed 78 women ranging from one to 60 months post diagnosis (for methodological issues regarding this study see Graham, 2000, p145 this dissertation). 95% of the women held causal attributes or theories about their cancer. The following categories were elicited, stress (41%), specific carcinogen (32%), heredity (26%), diet (17%), blow to the breast (10%) and other causes (10%). The authors found no support of the hypotheses that holding specific causal theories was related to better adjustment, however, when participants were asked to attribute responsibility for the cause of cancer to either the self, environment, chance or other people, blaming another person was correlated with poorer psychological adjustment.

Buick (1997) investigated causal beliefs in women undergoing chemotherapy or radiotherapy treatment for breast cancer. Seven relevant causal factors were reported by the participants; self blame, stress, extreme worry, marital discord, lack of emotional expression, chance and environmental hazards. The author suggested that self blame attributes may be adaptive or maladaptive, and that perceived control over the factor may determine its effect. For example, self-blame attributes may be adaptive if they focus on factors that are perceived to be controllable, such as dietary factors but maladaptive if they focused on factors beyond the individuals’ control. Buick found that those women who reported controllable self blame factors also reported engaging in modifying behaviours such as changing their diet.

In conclusion, most psychosocial research in breast cancer has focused on the period of diagnosis and treatment with only a small number examining the long-term impact on psychological adjustment. Furthermore the link between psychological adjustment and illness perceptions has been demonstrated during treatment for breast cancer and in other illness conditions (see Graham, 2000, p143- 147, this dissertation). However, no study has utilised this framework to explore the nature of illness perceptions in survivors of
breast cancer. The studies that have investigated adjustment amongst breast cancer survivors have either focused on one or two aspects of the self-regulatory model (e.g. beliefs about cause and control (Taylor et al, 1984) or simply attempted to measure adjustment without reference to illness perceptions.

**Aims of the study**

It was considered appropriate to adopt an exploratory strategy for the project, as the illness perceptions of women surviving breast cancer have not been extensively studied before. The study did not attempt to hypothesis test but to explore any relationships that exist between the variables.

The present study was designed to address two questions. Firstly, what relationship exists between cognitive representations of breast cancer, coping, anxiety and depression? This study aims to identify any relationship that exists between these variables.

Secondly, what is the content of illness perceptions in a sample of women survivors of breast cancer? As illness perceptions of women breast cancer survivors have not been widely studied a subsidiary aim was to describe the content of illness perceptions in this group.

**Methodology**

**Recruitment**

The research participants were selected from women who attended a breast care service of two hospitals in the South East of England. The project was submitted to the in-service ethics committee and gained ethical approval (see appendix one). The sample was drawn from a list of people who had surgical interventions for breast cancer in the last five years. At this stage, all men (N = 13), women with benign breast lumps and those known to have died were removed from the list. Women who had a recurrence of cancer were also excluded, as the project was addressing those who were recurrence free. For a discussion of anxiety and depression during diagnosis and treatment, see Graham (2000, p137-138, this dissertation).
To be included in the study the women must have received a diagnosis of breast cancer, had surgical intervention and finished active treatment for the cancer at least eighteen months ago. Surgical procedures are used to remove the cancerous growth: ranging from a lumpectomy where the cancerous growth is removed, to a mastectomy, where the skin, entire breast tissue and nipple are removed. Lymph glands are normally removed at this time, as the presence of cancer in the nodes is an indicator of the increased probability of future metastasis. Women with signs of metastases were excluded from the study.

Other exclusions were those women with non-invasive cancers; ductal or lobular carcinoma in situ (DCIS/ LCIS) where pathology is confined to the ducts of the breast and there is high "cure" rate (Webb and Koch, 1997). Ravdin (1997) asserted that these forms of cancer have no potential for metastases, have a very low risk of recurrence and do not require systemic therapy. This may result in very different psychological issues for this group as DCIS and LCIS differ from invasive breast cancers in important ways. For this reason it was decided to exclude these conditions from the study. Women over the age of 80 years were not included in the study as there was a very small number of women within this age group on the sampling list (N=2) and the medical notes indicated that they suffered from other major health problems.

The hospital records for each woman on the list were examined to confirm the diagnosis and to find a contact address and name of her GP. Information about the disease was noted, such as the grade of the tumor and possible lymph node involvement, which provided an indication of the associated prognosis. Ravdin (1997) concluded that both tumor size and number of involved axillary lymph nodes are independent predictors of disease free survival and overall survival for breast cancer patients. Breast cancer is often classified by the International Classification staging, which requires the assessment of tumour size and regional lymph involvement. This classification system is illustrated in Table 1.
Table 1. International classification of breast cancer

<table>
<thead>
<tr>
<th></th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>T1</td>
<td>Tumors of 2cm or less</td>
</tr>
<tr>
<td>T2</td>
<td>tumors of between 2 and 5cm</td>
</tr>
<tr>
<td>T3</td>
<td>Tumors over 5cm</td>
</tr>
<tr>
<td>T4</td>
<td>tumors fixed to the chest wall or skin of any size</td>
</tr>
<tr>
<td>N1</td>
<td>Mobile axillary nodes</td>
</tr>
<tr>
<td>N2</td>
<td>fixed axillary nodes</td>
</tr>
<tr>
<td>N3</td>
<td>nodes in neck, swollen arm</td>
</tr>
<tr>
<td>M0</td>
<td>no signs of metastases</td>
</tr>
<tr>
<td>M1</td>
<td>signs of metastases</td>
</tr>
</tbody>
</table>

A sample of 82 women who met the inclusion and exclusion criteria was drawn from the records of the breast care service. A letter was sent to each woman’s GP informing them of the study and asking them to notify the investigators if there were any reasons why their patient should not be contacted to take part. Two requests in total were made by the GPs not to contact a patient, leaving a sample size of 80. The reasons given by the GP were a) that the interview was likely to be too distressing and b) the woman did not have breast cancer but a benign breast lump.

Ideally, a larger number of women should have been invited to participate in the study, however several problems became apparent at this stage. Firstly, accessing the hospital notes to obtain the information necessary to decide on inclusion or exclusion was problematic. As many of the individuals on the sampling list were receiving regular follow-up appointments, their notes were often with medical staff and unavailable for examination. Without the medical notes it was impossible to confirm whether the individual had a diagnosis of breast cancer, had a benign breast lump or a non-invasive condition. Furthermore, GP names and patient addresses sometimes could not be found. If after repeated attempts to locate the medical notes failed, the individual was excluded from participation. This led to a reduced number of possible participants.

The next stage was to send a recruitment letter to those women meeting the criteria inviting them to take part in the study. If they were willing to take part they returned a
consent form to the investigator. The investigator then made telephone contact and arranged an interview. A 60% response rate was achieved and table 2 shows the number of letters sent out and the number of responses received. All research correspondence can be seen in appendix two.

**Table 2.** Number of letters sent and responses received

<table>
<thead>
<tr>
<th>Number</th>
<th>Percent (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recruitment letters sent</td>
<td>80</td>
</tr>
<tr>
<td>Respondents</td>
<td>48</td>
</tr>
<tr>
<td>Non respondents</td>
<td>29</td>
</tr>
<tr>
<td>Moved address</td>
<td>3</td>
</tr>
</tbody>
</table>

Table 3 lists the information known about the respondents and non-respondents. Differences between the respondents and non-respondents were explored using Mann-Whitney U for tumour grade, chi-square analysis for node involvement and marital status, and an independent sample t-rest for age. The results of these analyses are displayed in table 4. No statistically significant differences were found between the two groups and they appear to be broadly similar on all the variables obtained.

Ideally, it would have been beneficial to make comparisons between these two groups on variables such as socio-economic status and ethnicity but this information was not recorded routinely in the hospital notes.
Table 3. Characteristics of the respondents and non-respondents

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Respondents N= 48</th>
<th>Non Respondents N= 29</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>56.58</td>
<td>60.00</td>
</tr>
<tr>
<td>Standard deviation</td>
<td>12.49</td>
<td>11.66</td>
</tr>
<tr>
<td>Tumor grade</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>15 (31.3%)</td>
<td>11 (37.9%)</td>
</tr>
<tr>
<td>2</td>
<td>24 (50%)</td>
<td>14 (48.3%)</td>
</tr>
<tr>
<td>3</td>
<td>9 (18.8%)</td>
<td>4 (13.8%)</td>
</tr>
<tr>
<td>Node status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No node involvement</td>
<td>32 (66.7%)</td>
<td>16 (55.2%)</td>
</tr>
<tr>
<td>One or more positive nodes</td>
<td>16 (33.3%)</td>
<td>13 (44.8%)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>37 (77.1%)</td>
<td>19 (65.5%)</td>
</tr>
<tr>
<td>Divorced</td>
<td>4 (8.3%)</td>
<td>2 (6.9%)</td>
</tr>
<tr>
<td>Widowed</td>
<td>5 (10.4%)</td>
<td>6 (12.5%)</td>
</tr>
<tr>
<td>Single</td>
<td>2 (4.2%)</td>
<td>2 (6.8%)</td>
</tr>
</tbody>
</table>

Table 4. Results of analyses examining difference between participants and non-participants

<table>
<thead>
<tr>
<th></th>
<th>U</th>
<th>z</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mann-Whitney U</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tumour Grade</td>
<td>634.5</td>
<td>-.71</td>
<td>.48</td>
</tr>
<tr>
<td>Chi-square</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Node involvement</td>
<td>1.02</td>
<td>.31</td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
<td>1.98</td>
<td>.74</td>
<td></td>
</tr>
<tr>
<td>Independent sample t-test</td>
<td>T</td>
<td>DF</td>
<td>p</td>
</tr>
<tr>
<td>Age</td>
<td>-1.19</td>
<td>75</td>
<td>.24</td>
</tr>
</tbody>
</table>

It was not possible to interview 8 of the women who responded. The reasons for non-interview are given in Table 5.
Table 5. Number of participants interviewed and reasons for non-interview

<table>
<thead>
<tr>
<th>Reason</th>
<th>Number</th>
<th>Percent (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respondents</td>
<td>48</td>
<td>100</td>
</tr>
<tr>
<td>Further recurrence of cancer</td>
<td>2</td>
<td>4.2</td>
</tr>
<tr>
<td>Respondent cancelled interview</td>
<td>1</td>
<td>2.1</td>
</tr>
<tr>
<td>Changed mind due to crisis situation</td>
<td>2</td>
<td>4.2</td>
</tr>
<tr>
<td>(i.e. mother had stroke, husband died)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Response received after termination of data collection</td>
<td>3</td>
<td>6.25</td>
</tr>
<tr>
<td>Interviewed</td>
<td>40</td>
<td>83.3</td>
</tr>
</tbody>
</table>

Study Participants

Table 6 gives full details about those women who were interviewed for the study.

Table 6. Characteristics of the participants

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Frequency</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tumor grade</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I</td>
<td>10</td>
<td>25.0</td>
</tr>
<tr>
<td>II</td>
<td>22</td>
<td>55.0</td>
</tr>
<tr>
<td>III</td>
<td>8</td>
<td>20.0</td>
</tr>
<tr>
<td>Node status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No node involvement</td>
<td>28</td>
<td>70.0</td>
</tr>
<tr>
<td>One or more infected node</td>
<td>12</td>
<td>30.0</td>
</tr>
<tr>
<td>Type of surgery</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lumpectomy</td>
<td>23</td>
<td>57.2</td>
</tr>
<tr>
<td>Mastectomy</td>
<td>17</td>
<td>42.5</td>
</tr>
<tr>
<td>Adjuvant Chemotherapy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>24</td>
<td>60.0</td>
</tr>
<tr>
<td>No</td>
<td>16</td>
<td>40.0</td>
</tr>
<tr>
<td>Adjuvant Radiotherapy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>28</td>
<td>70.0</td>
</tr>
<tr>
<td>No</td>
<td>12</td>
<td>30.0</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>35</td>
<td>87.5</td>
</tr>
<tr>
<td>Widowed</td>
<td>2</td>
<td>5.0</td>
</tr>
<tr>
<td>Divorced</td>
<td>3</td>
<td>7.5</td>
</tr>
<tr>
<td>Ethnic background</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White - British</td>
<td>38</td>
<td>95</td>
</tr>
<tr>
<td>White - European</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Mean</td>
<td>56.85</td>
<td>11.69</td>
</tr>
<tr>
<td>Standard Deviation</td>
<td>11.91</td>
<td></td>
</tr>
</tbody>
</table>
Procedure

Each participant was interviewed face to face by the author in the participants' own home or at the hospital where they attended the breast clinic, according to their preference. Interviews were between 90 and 120 minutes in length. A face to face interview was selected as the most appropriate design for a number of reasons. Firstly, it was recognised that the subject matter of the research may be distressing to some individuals. A face to face interview was therefore appropriate to identify any distress caused and offer an opportunity to talk further about this. Davies, Hall, Clarke, Bannon and Hopkins (1998) conducted an interview study of terminally ill cancer patients and concluded that approximately 5% of interviewees were distressed by the interview experience. Therefore, it was considered important to provide participants who appeared distressed during or after the interview the opportunity to meet with a clinical psychologist working within the breast care service.

Secondly, an interview structure may reduce the number of possible biases operating. Although the investigator recognised that this may have led to some bias due to social desirability factors, other significant biases were avoided. For example, Bowling, Bond, Jenkinson and Lamping (1999) discuss the differences between postal designs and face to face interviews, with reference to the SF-36 (a general measure of health status). They argue that self administration may lead to order effects as the participant may read through the questionnaire before completing it and spend varying time periods completing the measure. They assert that an interviewer can assist with difficulties in completing questionnaires, clarify instructions and reduce the number of uncompleted questionnaires.

The research interview was divided into two sections. The first section asked about relevant information about the participant's illness (e.g. time of diagnosis, treatment received) and demographic information (e.g. age and occupation). A series of open-ended questions were included in this section. Participants were asked about personal theories or "hunches" about the cause of cancer, strategies they used to control the worry,
whether there had been any changes to their lives since having had cancer, whether these changes were for the better or worse and whether cancer could be controlled. Respondents were asked to rate the frequency they thought about recurrence on a Likert scale ranging from 1 (not at all) to 4 (a great deal of the time). The interview was based on interviews designed by Taylor, Lichtman and Wood (1984) and Buick (1997). Verbatim responses to these questions were recorded during the interview. The second part of the interview required the participants to complete a number of standardised questionnaires. A copy of the interview schedule and questionnaires used can be seen in appendix three.

Measures

The Illness Perception Questionnaire (IPQ)

The IPQ was developed by Weinman, Petrie, Moss-Morris and Horne (1996) as a method for assessing cognitive representations of illness. It is a theoretically derived instrument which provides information concerning the five components thought to underlie illness representations (identity, cause, time line, consequences and cure / control). The identity scale is comprised of 12 core symptom items that the respondent is asked to rate for frequency on a four point scale (from all the time to never). In addition it allows for the addition of items that are relevant to a specific illness group. Buick (1997) adapted the identity section of the IPQ in a study of women undergoing chemotherapy or radiotherapy for breast cancer. This adapted identity scale was utilised in the current study. The identity scale is scored by adding together the scores of the items that are rated as being related to breast cancer.

The items from time line, consequences and cure / control components are presented in a mixed order, and rated on a five point scale from strongly disagree to strongly agree. These scores are then added and divided by the number of items in the scale, after certain items are reverse scored. The cause items are rated on the same scale from strongly disagree to strongly agree. However, as the cause scale consists of separate causal beliefs it is not appropriate to sum all of these items and produce a total. In the present study,
the causal items were divided into physical and psychological / emotional *causes*, as utilised by Moss-Morris, Petrie and Weinman (1996). The items constituting psychological *causes* were emotional state, other people, own behaviour and stress and physical beliefs included a germ or virus, heredity, diet, pollution and poor medical care in the past.

Weinman et al (1996) found that the internal consistency of the IPQ scales excluding *cause* was in excess of 0.70 with *identity* and *consequences* both in excess of 0.80. Test-retest reliability is highest for the *control/cure* and *consequences* scales than the *identity* and *time line* scale. Weinman et al (1996) assert that this is to be expected as patients' perceptions of the *consequences* and cure of their illness are less likely to change over time.

*The COPE*

The COPE is a multidimensional coping inventory designed by Carver, Scheier and Weintraub (1986). It consists of sixteen subscales thought to be important in facilitating or obstructing adaptive coping. These subscales can be divided into problem and emotion focused coping (Moss-Morris, Petrie and Weinman, 1996) according to the process model of coping, alongside two scales labelled mental and behavioural disengagement. The COPE provides information about a wide range of coping behaviour, and includes several separate items for each subscale. The COPE was used in this study as it is a theoretically based questionnaire with good internal consistency and test-retest reliability. Internal consistency was acceptably good (Cronbach's alpha exceeded 0.6) for all subscales with the exception of the mental disengagement scale which is made up of a number of disparate items which is less likely to be internally consistent (Weinman, 1996). Test-retest reliabilities were calculated from two samples, six to eight weeks apart and these ranged from 0.42 to 0.89 for different scales (Weinman, 1996).

In this study, the author utilised four problem focused scales (active coping, planning, suppression of competing activities and seeking support for instrumental reasons), six
emotion focused scales (positive reinterpretation and growth, venting emotions, seeking instrumental social support, turning to religion, acceptance and denial) and two disengagement scales. These scales were also utilised by Moss-Morris et al (1996) who argued that these scales are the most relevant to illness groups.

Hospital Anxiety and Depression Scale (HADS)
The HADS was developed by Zigmond and Snaith (1983). The HADS is a 14 item questionnaire consisting of 7 items which measure anxiety and seven that measure depression. Each item is rated on a scale of 0, indicating no difficulty to 3, indicating a difficulty in this area. The measure was selected because it focuses on the cognitive symptoms of anxiety and depression and eliminates the somatic symptoms that are poor indicators of distress in physically ill populations (Payne, Hoffman, Theodoulou, Doski and Massie, 1999). It has been widely utilised in studies of mental health in women with breast cancer (e.g. Watson, Greer, Rowden, Gorman, Robertson, Bliss and Tunmore, 1991, Payne et al, 1999, Larsson, Peterson, Lampic, von Esses and Sjoden, 1998). The HADS provides cut off points which indicate clinical cases of anxiety and depression. Zigmond and Snaith (1983) recommend a cut off point of 8 and above for both anxiety and depression. However, to aid comparison, the more conservative cut off points suggested by Ellman and Thomas (1995) in a survey of anxiety and depression in breast cancer survivors were utilised (with a score of 0-7 considered well, a score of 8-10 as borderline and 11-21 as a clinical case).

Quantitative Analysis
Analysis was conducted using SPSS version 9 (Statistical Package for Social Sciences). Data screening was conducted following the procedure given by Altman (1991) and consisted of three phases (data checking, outliers and data screening). Data checking involved examining the data set for errors in the data. All categorical data was checked to ensure that the recorded values were meaningful, and continuous data (such as the HADS and IPQ) was checked in accordance with the specified lower and upper limits possible for each variable. As the study was an interview design there was no missing data. Data
screening involved checking each variable for univariate normality. With the exception of the HADS anxiety and depression scale, all variables were normally distributed. The results section gives details of transformations performed to achieve normality.

The HADS and IPQ have been treated as interval level data in many studies (e.g. Ellman and Thomas, 1995, Razavi et al, 1992 examining HADS, Moss-Morris et al, 1996, Scharloo, Kaptein, Weinman, Bergman, Vermeer and Rooijmans, 2000, utilising the IPQ). These questionnaires are thought to produce interval level data, with an equal interval between scores. Therefore it was considered appropriate to use parametric tests.

When designing the study, it was envisaged that regression analyses would be used to investigate the relationship between illness representations, coping and psychological adjustment (anxiety and depression). To ensure adequate power to detect a medium sized relationship, the required number of participants was determined using a formula provided by Tabachnik and Fidell (1996). This formula suggested that 106 participants were necessary (where $\alpha = 0.05$ and a power of 0.80). However, due to difficulties in recruitment and limited time available for data collection, a much smaller sample size of 40 was achieved and this meant that it was no longer possible to use regression analyses due to insufficient numbers. Pearson's correlations were selected as an appropriate method of examining associations in the sample.

As the sample size was small (N=40), the concern was with type 2 errors, not finding a statistically significant correlation when there is one. Statistical corrections for the number of correlations would make type 2 errors more likely by reducing the level of significance. Altman (1991) argues that using corrections for multiple tests has the disadvantage of being conservative as they err on the side of safety (non-significance), and that the Bonferroni method is highly conservative. The author decided not to use this correction and accept the possibility of type 1 errors (finding a significant relationship when there is none) and acknowledging that possibility that some correlations may be spurious.
Semi-structured interview

The IPQ is a general questionnaire that can be used with people with a variety of illness conditions (e.g. chronic fatigue, rheumatoid arthritis, diabetes). It requires the participants to rate a series of statements as true or false and produces an overall score for each of the components (with the exception of cause). However, it does not provide information about the content of illness perceptions. As survivors of cancer are in an unusual position, neither clearly ill nor clearly healthy (Fallowfield and Clark, 1991) this position may be reflected in their illness perceptions. For this reason it was decided to be important to investigate the content of illness perceptions, and therefore open-ended questions were asked to elicit the content of each participant's illness perceptions. Appendix three contains a copy of these questions.

Content analysis was selected to analyse the qualitative data derived from the open questions. The overall aim of content analysis is to extract meaning from verbal data and allow for further analysis, often in terms of frequency of occurrence of categories or themes. Content analysis allows for the analysis of verbal data in a systematic, objective and quantitative manner (Pauli and Bray, 1998). Content analysis has two components, the mechanical and the interpretative (Krippendorf, 1980 cited by Millward, 1995). The mechanical component is concerned with the organisation and subdivision of data into categories developed by the researchers, whereas the interpretative component is concerned with deciding which of the categories are meaningful in relation to the research questions.

Analysis of the verbatim responses to the open ended questions was conducted to identify the content of illness perceptions. Responses to each question were grouped into categories containing similar statements. These categories were then given a descriptive label that indicated their content. The verbatim quotes and the categories to which they were allocated, are presented in appendix four. As criticisms have been made of
The responses to each question were given to a researcher working within the breast cancer field. The researcher was asked to independently allocate the participants' responses to each open-ended question to the descriptive categories provided. The number of items that the author and researcher placed in the same category was calculated, as was the number of disagreements. The kappa statistic was calculated to compare the ratings of the two assessors ($\kappa = 0.93$), indicating good agreement between the two assessors.

**Results**

One aim of the study was to explore the relationship between illness perceptions, coping and anxiety and depression in the sample. These relationships were examined by means of correlational analyses. The correlations between illness perceptions and anxiety and depression will be presented first, followed by the correlation between coping and anxiety and depression.

The second part of the results section presents content analyses of participants' illness perceptions derived from the semi-structured interview. The results are presented for each question separately, with the categories developed and illustrative quotes presented in table form.

*Anxiety and depression*

Table 7 illustrates the HADS score for the sample. 10% and 25% of the sample scored within the clinical and borderline range respectively for anxiety. In contrast, very few of the participants scored within the borderline or clinical range for depression (both 5%).
Table 7. Hospital Anxiety and Depression Scale scores of the participants.

<table>
<thead>
<tr>
<th>Well (score 0-6)</th>
<th>Borderline (score 7-10)</th>
<th>Case (score 11-21)</th>
<th>Mean Score (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>N (%)</td>
<td>N (%)</td>
<td>N (%)</td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>26 (65)</td>
<td>10 (25)</td>
<td>4 (10)</td>
</tr>
<tr>
<td>Depression</td>
<td>36 (90)</td>
<td>2 (5)</td>
<td>2 (5)</td>
</tr>
</tbody>
</table>

The distributions for both anxiety and depression scores within the sample were positively skewed (anxiety skewness = 1.05, s.e. skewness = .37, z = 2.8, depression skewness = 2.062, s.e. skewness = 0.37, z = 5.313). As an assumption of parametric tests is that data should be drawn from a sample that is normally distributed, a logarithmic transformation was utilised and all correlations were conducted using the transformed anxiety and depression data.

Time since diagnosis

Previous research has found that the time that has passed since the initial diagnosis and end of treatment influences levels of anxiety and depression. A Pearson's correlation was conducted to examine this relationship (see Table 8).

Table 8. Pearson's Correlation of Months Since Treatment Ended and Anxiety and Depression.

<table>
<thead>
<tr>
<th>Anxiety Correlation coefficient</th>
<th>P</th>
<th>Depression Correlation coefficient</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Months since diagnosis</td>
<td>.321</td>
<td>.043</td>
<td>.118</td>
</tr>
</tbody>
</table>

There was a statistically significant moderate positive correlation between anxiety and time since diagnosis (p = <0.05), with anxiety increasing as time since diagnosis.
increased. There was no statistically significant correlation between months since diagnosis and levels of depression as measured by the HADS.

Further tests were carried out to investigate the correlation between anxiety, depression, and other possible confounding variables (e.g. age, tumor grade and node involvement). No statistically significant results were obtained, and the results of these analyses are summarised in appendix five.

**Illness perceptions**

Table 9 illustrates the mean score on the IPQ for the *identity, control/cure, consequences* and *time line* components. The IPQ *cause* items were divided into physical and psychological attributes, as described earlier. The pollution attribute however, was not highly correlated with the other physical items so was kept as a separate item for the purpose of analysis.

<table>
<thead>
<tr>
<th>IPQ Subscale</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identity</td>
<td>5.15 (2.90)</td>
</tr>
<tr>
<td>Time line</td>
<td>2.38 (1.00)</td>
</tr>
<tr>
<td>Consequences</td>
<td>2.83 (0.90)</td>
</tr>
<tr>
<td>Control/cure</td>
<td>3.53 (0.54)</td>
</tr>
<tr>
<td>Psychological attribute</td>
<td>2.76 (0.99)</td>
</tr>
<tr>
<td>Pollution attribute</td>
<td>3.33 (1.27)</td>
</tr>
<tr>
<td>Physical attribute</td>
<td>2.48 (0.66)</td>
</tr>
</tbody>
</table>

The mean score for the *identity* component was five out of a possible 15 physical symptoms. This indicates that women survivors continue to experience physical symptoms related to breast cancer some time after the initial surgery and treatment.

As outlined earlier, the *control/cure, consequences* and *time line* scales have a total score between 1 and 5, with a score of 1 representing a strong negative belief in the items, a score of 3 represents "neither agree nor disagree", and five a strong positive belief. The
control/cure mean score was 3.5, indicating a small positive belief in the possibility of cure or control of cancer. The consequences mean score of 2.71 reflects a belief that cancer does not have serious consequences and the time line score of 2.33 represents a belief in an acute time line (lasting a short time and a temporary condition rather than a permanent one). Pollution, followed by psychological causes were judged to be the most likely cause for breast cancer. Physical attributes were rated as least likely to be the cause. This is in contrast to the medical literature which suggested that hormones, genetic factors (both physical factors), diet and alcohol may be risk factors for the development of breast cancer (Henderson and Feigelson, 1997).

Ilness perceptions in relation to anxiety and depression

Tests of correlation were utilised to examine the relationship between anxiety, depression and illness perceptions as measured by the IPQ. A summary of these analyses is presented in Table 10.

Table 10. Pearson's Correlation analysis of anxiety and depression with illness perceptions

<table>
<thead>
<tr>
<th>Illness Perceptions</th>
<th>Anxiety</th>
<th>Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Correlation coefficient</td>
<td>p</td>
</tr>
<tr>
<td>Identity</td>
<td>.43</td>
<td>.005</td>
</tr>
<tr>
<td>Time line</td>
<td>.26</td>
<td>.100</td>
</tr>
<tr>
<td>Consequences</td>
<td>.35</td>
<td>.026</td>
</tr>
<tr>
<td>Control / cure</td>
<td>-.31</td>
<td>.055</td>
</tr>
<tr>
<td>Physical attribute</td>
<td>-.05</td>
<td>.756</td>
</tr>
<tr>
<td>Psychological attribute</td>
<td>.13</td>
<td>.423</td>
</tr>
</tbody>
</table>

The identity component showed a low to moderate positive correlation with anxiety and depression, meaning that anxiety and depression increased as the number of illness identity symptoms increased. There was a low positive correlation between anxiety and consequences, meaning that as anxiety increased the number of perceived consequences
of breast cancer also increased. The control/cure or time line components showed no statistically significant correlation with HADS anxiety or depression. Although there were no statistically significant correlations between holding a psychological, physical or pollution attribution about the cause of breast cancer and anxiety or depression, there was a trend towards a significant positive correlation between physical causes and anxiety.

**Coping in relation to anxiety and depression**

Coping strategies represent a variable that may influence the level of anxiety and depression in survivors of breast cancer. Figure 1 illustrates the coping styles reported by the participants. The most used strategies reported by the participants were acceptance, active coping, positive reframing and growth and planning.

**Figure 1.** Mean coping styles reported

![Diagram of coping styles](image)

<table>
<thead>
<tr>
<th>COPE Subscale</th>
<th>'Usually don't do this at all'</th>
<th>'Do this a little bit'</th>
<th>'Do this a medium amount'</th>
<th>'Do this a lot'</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behavioural Disengagement</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Denial</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Religion</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental Disengagement</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Seeking Instrumental Support</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Venting Emotions</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Suppression of Competing Activities</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Seeking Emotional Support</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Planning</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Positive Reinterpretation &amp; Growth</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Active Coping</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acceptance</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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Correlational analyses were used to examine the relationship between anxiety, depression, problem and emotion focused coping as measured by the COPE. The results of this correlation can be seen in Table 11.

**Table 11. Pearson's Correlation between Coping, Anxiety and Depression Scores on the HADS.**

<table>
<thead>
<tr>
<th>Coping Subscale</th>
<th>Anxiety</th>
<th>Depression</th>
<th>Anxiety Correlation</th>
<th>Depression Correlation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>P</td>
<td>co-efficient</td>
<td>p</td>
</tr>
<tr>
<td>Emotion focused coping</td>
<td>10.4 (2.3)</td>
<td>.12</td>
<td>.46</td>
<td>-.27 .09</td>
</tr>
<tr>
<td>Problem focused coping</td>
<td>9.7 (1.5)</td>
<td>-.02</td>
<td>.93</td>
<td>-.09 .60</td>
</tr>
<tr>
<td>Behavioural disengagement</td>
<td>5.8 (1.9)</td>
<td>.16</td>
<td>.32</td>
<td>-.02 .92</td>
</tr>
<tr>
<td>Mental disengagement</td>
<td>8.4 (2.4)</td>
<td>.18</td>
<td>.27</td>
<td>.06 .69</td>
</tr>
</tbody>
</table>

There were no statistically significant correlations between levels of anxiety or depression and emotion or problem focused coping, mental or behavioural disengagement.

Ideally, it would have been useful to carry out a multiple regression to examine which variables were the strongest predictors of anxiety and depression. An a priori power calculation was undertaken to ensure adequate power to detect a medium sized relationship between the variables. However, as outlined on page 179, the required number of participants was not achieved, the technique would not have enough statistical power to detect medium or small relationships and was not employed.

**Content of illness perceptions of breast cancer**

**Identity**

The participants were asked to describe any current symptoms they were experiencing as a result of having had breast cancer or treatment. Table 12 illustrates the responses given by the participants. The most common physical complaint was a restriction of arm movement leading to difficulties with lifting. This was reported by 37.5% of the sample. 27.5% of the sample experienced pain at the site of surgery and 27.5% reported...
numbness under the arm or in armpit, followed by tiredness (22.5%), swollen arm or lymphedema (22.5%), weight gain (17.5%) and hot flushes (7%) (both attributed to hormone therapy). A small number of participants mentioned gynaecological problems, an unpleasant taste attributed to radiotherapy, aching legs and headaches (all 5%).

Table 12. Current physical symptoms related to cancer or its treatment, as reported by the participants

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Restricted movement in arm / shoulder</td>
<td>15</td>
</tr>
<tr>
<td>Pain around breast scar</td>
<td>11</td>
</tr>
<tr>
<td>Numbness under arm</td>
<td>11</td>
</tr>
<tr>
<td>Tiredness</td>
<td>9</td>
</tr>
<tr>
<td>Swollen arm / lymphedema</td>
<td>9</td>
</tr>
<tr>
<td>Weight gain</td>
<td>7</td>
</tr>
<tr>
<td>Hot flushes</td>
<td>4</td>
</tr>
<tr>
<td>Unpleasant taste in mouth</td>
<td>2</td>
</tr>
<tr>
<td>Aching legs</td>
<td>2</td>
</tr>
<tr>
<td>Headaches /migraine</td>
<td>2</td>
</tr>
<tr>
<td>Gynaecological problems</td>
<td>2</td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
<tr>
<td>- depression</td>
<td>1</td>
</tr>
<tr>
<td>- nerves</td>
<td>1</td>
</tr>
<tr>
<td>- hair loss</td>
<td>1</td>
</tr>
<tr>
<td>- 'messed up' nervous system</td>
<td>1</td>
</tr>
<tr>
<td>- dermatitis</td>
<td>1</td>
</tr>
</tbody>
</table>

The symptoms attributed to cancer are similar to the list of symptoms contained on the breast cancer specific identity subscale of the IPQ (Buick, 1997). Symptoms that were not contained on the IPQ included gynaecological problems, unpleasant tastes, restricted movement, numbness and swollen arms. The items on the identity scale of the IPQ perhaps reflect the symptoms typical during and immediately following treatment, rather than those experienced many months after treatment has ended.

Consequences
The participants were asked to describe the effect that having cancer had on their current lifestyles, many months after diagnosis and treatment finishing. Table 13 illustrates the positive and negative effects as rated by the participants.

Table 13. Frequency of positive and negative lifestyle changes reported

<table>
<thead>
<tr>
<th>Positive changes</th>
<th>Frequency</th>
<th>Negative changes</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diet (e.g. eating more fruit and vegetables, cut out red meat, become vegan)</td>
<td>8</td>
<td>Sexuality / body image (e.g. loss of interest in sex, self-conscious, loss of femininity)</td>
<td>7</td>
</tr>
<tr>
<td>Increase in fitness / health (e.g. exercise more, given up smoking, lost weight)</td>
<td>8</td>
<td>Physical changes (e.g. more tired, dermatitis and loss of appetite - as effects of treatment)</td>
<td>8</td>
</tr>
<tr>
<td>Better at dealing with stress (e.g. I've calmed down, taken up yoga, better at recognising stress)</td>
<td>8</td>
<td>Worse at dealing with stress (e.g. I get more uptight than I used to, I'm more tearful than I used to be)</td>
<td>3</td>
</tr>
<tr>
<td>Career change / more enjoyable job (e.g. doing things that I enjoy. Helping with gardening)</td>
<td>3</td>
<td>Cut down work / unable to work (e.g. went back to work but couldn't settle or cope with stress)</td>
<td>5</td>
</tr>
<tr>
<td>Working time reduced (e.g. cut down work and more time for family)</td>
<td>3</td>
<td>Restricted activity (e.g. can't garden anymore)</td>
<td>7</td>
</tr>
<tr>
<td>Increased assertion / self value (e.g. I'm prepared to say no more, more self worth and value)</td>
<td>3</td>
<td>Mood changes (e.g. more irritable, depressed, anxious)</td>
<td>4</td>
</tr>
<tr>
<td>New activities (e.g. reflexology course, poetry, sculpture and painting)</td>
<td>4</td>
<td>Relationships/Other people (e.g. family treat me as china, avoid meeting new people)</td>
<td>2</td>
</tr>
</tbody>
</table>
The most common positive change attributed to cancer was a change in diet, an increased health/fitness level and ability to cope with stress. The most frequently mentioned negative consequence attributed to breast cancer was a change in physical health and sexuality. A similar proportion of positive and negative changes attributed to cancer were described (37 positive and 36 negative).

**Control / cure**

Participants were asked about their beliefs about the control of cancer and whether it would come back or not. Very few participants believed that they had any personal control over whether they had a recurrence in the future. Table 14 lists the responses to this question.

**Table 14. Participants' views about Control of cancer**

<table>
<thead>
<tr>
<th>Response</th>
<th>Illustrative examples</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive thinking / attitude</td>
<td>The way you think can affect cancer. If you spend time thinking about it, it will come back. You can control cancer by positive thinking. My mind is powerful. Attitudes make a big difference. Some people frighten themselves to death</td>
<td>7</td>
</tr>
<tr>
<td>Removing stress</td>
<td>Can control cancer by removing stress from your life. If I went back to my old job it would all come back. Friend had turbulent love life which made her situation worse.</td>
<td>3</td>
</tr>
<tr>
<td>Diet</td>
<td>Can protect self from cancer by avoiding certain foods. Eat organic fruit and vegetables. It's a cushion between me and it coming back.</td>
<td>2</td>
</tr>
<tr>
<td>Hormone therapy</td>
<td>If you're on tablets - they prevent cancer, but you can still get it.</td>
<td>1</td>
</tr>
<tr>
<td>Alternative therapies</td>
<td>I'm into alternatives.</td>
<td>1</td>
</tr>
<tr>
<td>Increased fitness</td>
<td>Building up body.</td>
<td>1</td>
</tr>
</tbody>
</table>
Positive thinking was the most frequently cited way of controlling the cancer, or stopping it recurring. Other strategies mentioned were removing stress, diet, hormone therapy, alternative therapy, and increasing fitness. In contrast to other medical conditions, there are few active medical interventions available once the initial surgery, and adjuvant therapy have been completed. Medical follow-up is designed to identify any recurrence or spread at an early stage, rather than recommend any active treatment or intervention. Although many women mentioned still taking adjuvant hormone therapy, only one participant viewed this as helping to control the cancer.

**Cause**

Content analysis of the personal theory section of the interview identified seven causal theories: stress and life events, psychological factors / own characteristics, chance/fate, environmental hazards, hormones, lifestyle choices and genetic/hereditary factors. Table 15 lists the personal causal theories and gives examples of each.

**Table 15. Personal Theories about Cause of Breast Cancer.**

<table>
<thead>
<tr>
<th>Theories / hunches</th>
<th>Illustrative examples</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stress / Life events</td>
<td>I had a very stressful life. I had to be the stronger partner. I'm not surprised I got cancer. In the ward all the ladies I spoke to had stressful lives. Surgeon reckoned it had been growing for a year. During that year my husband was made redundant, I was unhappy and my son was ill.</td>
<td>15</td>
</tr>
<tr>
<td>Injury / Trauma to breast</td>
<td>My grandson hit me with a toy on my breast in the same place. Maybe bonks and falls. My dog got knocked down and within a year he got leukaemia.</td>
<td>8</td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th>Genetic / Hereditary Factors</th>
<th>Once I was diagnosed aware that grandmother and aunt had breast cancer but were shy of talking about it. Runs in the family.</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lifestyle and Personal Choice e.g. Diet, job, smoking</td>
<td>Milk left in the nipple whilst breast feeding. Altitude. Used to be long haul stewardess.</td>
<td>6</td>
</tr>
<tr>
<td>Hormones / menopause</td>
<td>Taken hormone tablets for headaches. Hormone replacement therapy or menopause.</td>
<td>6</td>
</tr>
<tr>
<td>Environmental Hazards</td>
<td>Geophysical stress- a river runs underneath my old work. Four people are off long term with cancer. The airport. Three of us neighbours have cancer. Aircrafts dump fuel into the atmosphere.</td>
<td>4</td>
</tr>
<tr>
<td>Fate / Luck / chance</td>
<td>It's fate. It's just something that happens.</td>
<td>3</td>
</tr>
<tr>
<td>Psychological factors/ own characteristics</td>
<td>Life has always been about caring and giving. I've given too much. I was not a strong person. I used to think I wished it on myself. Used to hear about people who had cancer, I worked at the hospice. I wonder if I wished it on. That plays on my mind.</td>
<td>2</td>
</tr>
<tr>
<td>Other theories</td>
<td>Pain causes cancer. It's punishment for a former life.</td>
<td>1</td>
</tr>
</tbody>
</table>

The frequency reported in the table exceeds the number of participants, as some women selected more than one possible causal theory or "hunch".

*Coping with the fear of recurrence*

Participants were asked to describe how they dealt with the possibility of cancer recurring. Table 16 displays the ways that participants dealt with this fear. Cognitive strategies such as thought blocking, distraction and positive thinking were reported frequently. Examining the breast or paying attention to physical symptoms which may indicate recurrence were commonly reported. Once again, the numbers of strategies reported may exceed the number of participants, as some participants discussed more than one method of dealing with the fear of future recurrence.
Table 16. Reported means of coping with fear of recurrence

<table>
<thead>
<tr>
<th>Coping strategy</th>
<th>Illustrative Examples</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cognitive strategies</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Put a mental block down.</td>
<td>I think positive thoughts like 'I'm not going to let this beat me'.</td>
<td>16</td>
</tr>
<tr>
<td><strong>Vigilance / checking</strong></td>
<td>If I can't feel any lumps I must be alright.</td>
<td>13</td>
</tr>
<tr>
<td><strong>Put it behind me/ carry on with life</strong></td>
<td>You could stop living. I'd rather die and be happy.</td>
<td>5</td>
</tr>
<tr>
<td><strong>Fate</strong></td>
<td>If it comes back it will. I can't live forever.</td>
<td>3</td>
</tr>
<tr>
<td><strong>Gather evidence</strong></td>
<td>I did lots of reading... talked to friends who had it and they're ok.</td>
<td>1</td>
</tr>
<tr>
<td><strong>Religion / faith</strong></td>
<td>I've got the Lord on my side. He will help me through.</td>
<td>2</td>
</tr>
<tr>
<td><strong>Planning for future</strong></td>
<td>I need to be realistic. Made plans to deal realistically with death.</td>
<td>2</td>
</tr>
</tbody>
</table>

Discussion

A brief summary of the main results of the study will be presented before the detailed discussion of the findings. The overall aim of the study was to explore the relationship between illness perceptions and coping with anxiety and depression in women surviving breast cancer. Two components of illness perceptions were significantly correlated with anxiety or depression; identity was positively correlated with both anxiety and depression and a belief in the serious consequences of breast cancer was positively correlated with levels of anxiety. No significant correlation was found between coping and anxiety or depression. The content analysis of illness perceptions revealed a variety of symptoms contributing to illness identity, and equal numbers of positive and negative consequences of breast cancer. Few ways in which cancer can be controlled or cured were reported and the personal theories of the cause of cancer varied from current medical consensus.
**Anxiety and depression**

A substantial minority of the sample scored within the clinical and borderline range for anxiety on the HADS (10 and 25% respectively). However, mean the score for depression on the HADS was extremely low, with only 10% of the sample scoring within the borderline and clinical range. These scores are broadly similar to those obtained by Ellman and Thomas (1995) who compared breast cancer survivors and matched controls (women without cancer attending for screening). The authors found that 27% of breast cancer survivors scored within the borderline and clinical range for anxiety and 9% scored within the same range for depression.

The low depression scores could indicate three possibilities: that the level of depression is very low in breast cancer survivors, depression was under reported or that there was a problem using the HADS depression scale with this population. A recent study by Hall, O'Hern and Fallowfield (1999), published after data collection had begun, compared clinical interviews with the HADS self-report questionnaire in women with early stage breast cancer. Clinical interviews identified anxiety disorder in 132 of 266 women and depressive illness in 99 of 266 women (49.6% and 37.2% respectively). Using the recommended threshold for caseness, the sensitivity of the HADS was very low with only 24.2% and 14.1% exceeding the cut off scores for anxiety and depression. The authors concluded that the HADS was an inadequate instrument for ascertaining depressive illness, and question the use of the HADS as a screening instrument in the detection of psychological morbidity in breast cancer.

One of the surprising findings of the research is that anxiety increases as the time since diagnosis increases. This is in contrast to other research findings that indicate anxiety reduces over time. For example Derogatis (cited in Welch-McCaffrey, Hoffman, Leigh, Loescher, Meyskens, 1989) argued that the psychosocial impact of cancer in survivors lessened with time.
It is possible that as time from diagnosis increases, the anxiety associated with the initial trauma of diagnosis, dealing with the surgery and adjuvant therapy may have subsided, but other concerns about recurrence in the future may be emerging. To illustrate this hypothesis, quotes by participants discussing their concerns about recurrence are utilised:

"I worry this is going to get worse. Will I get it in the other breast?"

"Sometimes I get an odd pain and I think is that cancer?"

"It's there every day (worry about recurrence). It never goes away. Something reminds me and it comes into my mind. Tend to check yourself more, far more frequently than before"

"When you hear about x, she had money but still you can't stop it. I never feel as if I've got away with it, always a threat at the back of my mind"

Also as the time since diagnosis approaches 5 years, hospital follow up appointments cease and adjuvant hormone therapy may stop. Hormone therapy can be considered by the women to be a reassuring, safety measure to prevent further relapse, for example participants commented:-

"What will happen when I stop taking tamoxifen?"

"As I get nearer to five years, am I going to be alright?"

It is also possible that the anxiety scores reflect other life stresses that are not cancer related. Mental health problems may be the result of coincidental, other life event or social difficulties, past history or recurrent depression (Hughes and Lee, 1988). Although these were not directly asked about during the interview, information concerning other life stresses were mentioned during the interview. For a few women there had been an obvious life event that may have elevated their HADS scores (one participant had been bereaved, one had relationship difficulties), but for the majority of women, as far as the limited data collected is concerned, there were no obvious psycho-social stressors that could be contributing to an increase in anxiety over the time period concerned.
Illness perceptions, anxiety and depression

The overall aim of the study was to explore the relationship between illness perceptions and anxiety and depression in women surviving breast cancer. Identity was positively correlated with both anxiety and depression. A belief in the serious consequences of breast cancer was positively correlated with levels of anxiety.

First, although these relationships were statistically significant at the 0.05 level, there is a chance that they could represent spurious correlations due to the number of correlations calculated. In order to make sense of these correlations, two factors need to be considered; the magnitude of the correlations and whether these findings are similar to those of other studies.

Altman (1991) states that the magnitude of the correlation that is significant at the 5% level depends upon the sample size. It is therefore important to examine the magnitude of correlation along with the statistical probability that the relationship is a real one and not due to chance. The correlations between identity and anxiety are low to moderate. If $100r^2$ is calculated, (the percentage of the variability in the two variables that is explained by the association) it implies that only 18.5% of the variability can be explained by the relationship between anxiety and identity, and just 12.3% of the variability between anxiety and consequences. This figure drops to just 10.2% of the variance between identity and depression.

It is not possible to infer causality using correlational analyses and when significant associations between variables are found, all findings will be strengthened by confirmation (Altman, 1991). The finding that a strong illness identity and a belief in serious consequences of breast cancer correlated with anxiety scores on the HADS is consistent with findings in other illness conditions. For example, Heijamns (1999) examined the role of illness perceptions in Addison's disease, a chronic disease that has a wide variety of non-specific symptoms such as weakness, fatigue, weight loss and gastrointestinal symptoms which have a biological basis in adrenal insufficiency.
(Heijmans, 1999). The author found that a belief in frequent and serious symptoms was associated with higher levels of disability in physical, social and mental health functioning.

The relationship between depression and a strong illness identity has also been demonstrated by previous research. For example, Woods and Earp (1978) found a relationship between the extent of physical symptoms and a depression following mastectomy. Those women who reported more physical symptoms were also more likely to report a higher number of symptoms of depression.

In contrast to research in other illness conditions, no link between holding a psychological causal attribute and anxiety and depression levels was found. However, there was a trend towards statistical significance between a belief in the physical causes of breast cancer and anxiety. The physical cause attribute was made up from items relating to heredity, a germ or virus, poor medical care in the past, and diet. With the exception of diet, these causal factors place the responsibility outside of the realm of personal accountability. One might hypothesise that it could be more psychologically adaptive to hold an external attribute for cancer than an internal one.

*Psychological adjustment and coping*

No relationship between coping strategies and psychological adjustment was found in the study. One reason for the lack of relationship between anxiety, depression and coping may be explained by the crude division between problem and emotional focused coping. Leventhal et al (1997) discuss the problems with using single factors for problem based coping, which may include strategies such as dietary change, exercise, and treatment for the illness. Although it is desirable to examine each coping strategy separately, this would have increased the number of correlations necessary (as there are 12 separate coping strategies listed on the COPE).
A second possibility is that the relationship observed was an accurate one, and that coping cannot adequately explain psychological adjustment. The same coping procedure could be considered either adaptive or maladaptive depending on the individual using the strategy and the meaning it has for them. Qualitative information obtained indicated that responses within the same descriptive category may have different meanings. For example, one participant commented that she did not "allow" herself to think of the possibility of recurrence, perhaps indicating overwhelming anxiety about recurrence, whereas another woman reported that she "didn't dwell" on thoughts of recurrence because it affected her mood (made me feel down). Both of these responses were summarised within the 'cognitive strategies' category, but may reflect very different meanings to the individuals concerned.

A third possibility concerns the sensitivity of the HADS in detecting levels of depression in this population. Research by Hall et al (1999) raised doubts concerning the ability of the HADS to detect depression. As the mean depression score in the present study was low, with a small standard deviation (mean = 2.80, standard deviation = 2.89), it is highly unlikely that any correlations would be found between this and any other variable.

**Content of illness perceptions**

Overall, the analysis of the content of illness perceptions revealed a similar pattern to that found with the IPQ. Participants reported a variety of physical symptoms contributing to their illness identity, and balanced views concerning the likely positive and negative consequences of their illness.

However, participants mentioned very few ways in which cancer could be controlled or cured. The mean score on the IPQ approached a score of 4, which represents an agreement in the possibility of control or cure of cancer. An explanation for this finding is that the IPQ was measuring beliefs concerning the possibility that the condition has been cured and can be controlled, whereas the open ended questions seemed to generate strategies for preventing future recurrence without reference to a perceived cure.
There were some items generated by participants that were not included in the adapted *identity* component of the IPQ (Buick, 1997), such as gynaecological problems, unpleasant taste, restricted movement and swollen arms. The addition of an open ended item to the *identity* section of the IPQ investigating other symptoms which are perceived to be part of the condition could prove useful.

It is interesting to note that the personal theories or "hunches" of causality held by the participants varied substantially from current medical consensus. The wide range of causal beliefs is consistent with a number of studies reporting attributes such as self-blame, stress (Buick, 1997, Taylor et al 1984), marital discord and environmental hazards (Buick, 1997). The idea of a lack of emotional expression, the type C personality (Temoshok and Dreher, 1991), could overlap with the category of psychological characteristics but was not a common causal attribution. Buick (1997) argues that the wide range of causal beliefs evident in women with breast cancer may reflect the current state of uncertainty surrounding the disease and that this may lead patients to search for an explanation. It may also be an indicator of the lack of information about current evidence disseminated by health care professionals. Luker, Beaver, Leinster and Owens (1996) argued that information giving is often limited to the time of diagnosis despite evidence that attention and recall are limited during life threatening situations. This could mean that women could not recall accurately the information relayed to them, due to high levels of stress.

**Clinical relevance**

Psychological morbidity is an important issue within breast cancer. It is clear that anxiety and depression are detrimental to an individual's quality of life, but in breast cancer there is preliminary evidence that an important relationship between survival rates and psychological well-being exists and requires further study. For example, Watson, Haviland, Greer, Davidson and Bliss (1999) examined the relationship between psychological response and disease outcome in a large sample of women diagnosed with...
early breast cancer (N=578). They found that women with a high depression score on the Hospital Anxiety and Depression Scale had an increased rate of death from all causes. Furthermore, those women who had a high score on the helplessness and hopelessness scales of a coping questionnaire had a higher rate of relapse or death by 5 years than those participants with lower scores. This study illustrates the importance of continuing to examine anxiety and depression in cancer, and factors which may well influence psychological adjustment are of great clinical relevance. The current study indicates that a substantial proportion of the sample experienced mild to moderate anxiety levels.

Another significant finding was that anxiety increased as time since completion of treatment increased. This suggests a continuing role for health professionals in the identification of cancer related distress after the completion of treatment. One participant commented:

"When it's all over (the treatment), suddenly everything's back to normal. They want to shut it out. I was left with a blank void. I found that difficult to cope with. I'm not the same person".

Service contact reduces as time since diagnosis increases, which leaves little time to deal with psychosocial issues or concerns. Ongoing support may be useful in assisting survivors in the adaptation to psychosocial stresses of survivorship and may minimise adjustment difficulties. Welsch-McCaffrey et al (1989) concluded that an extension of support from those who are treatment focused into the phase of post therapy evaluation and guidance is needed. Qualitative data illustrated the negative effects that cancer survival can have on life, including body image and sexuality issues, physical symptoms, restricted activity, mood changes, changes in relationships with others and employment issues. Information about coping with psychosocial stresses generated by survivorship could be provided and the normalization of common concerns such as physical numbness (Polinsky, 1994).
Furthermore, clinical psychologists may have a role to play in addressing negative illness perceptions. A logical conclusion is that if attempts are made to influence or challenge unhelpful illness perceptions, this may lead to a change in mood and adjustment. Kemp et al. (1999) assert that interventions within a cognitive behavioural focus aimed at modifying certain illness cognitions to improve psychological adjustment would be fruitful areas of research. Further research would be necessary to outline both procedures for working therapeutically with illness perceptions and the therapeutic value of doing so.

The low level of depression found using the HADS, could support the conclusions of Hall et al. (1999), that the HADS was an inadequate research tool to assess depression in women with breast cancer. This is an important issue, as the HADS is a widely used screening measure to assess adjustment in this population. If the HADS suffers from a low sensitivity, research studies may wrongly conclude that levels of depression in breast cancer survivors are low. This has major implications both for individuals and service development. For example, Payne et al. (1999) used the HADS to screen for psychological difficulties in patients attending outpatient oncology clinics. The authors concluded that the HADS was a useful method of documenting the need for mental health services. If the HADS is found to be insensitive in detecting depression, the needs of this group may be underestimated and consequently under resourced. Further research is necessary to compare the HADS with other methods of assessing depression (e.g. clinical interview or alternative self-report measures).

Limitations
One of the main limitations of the study is the small number of participants. When the study was designed, a larger number of participants was envisaged. However, due to limits on the time and resources available, it was not possible to increase the number of participants. The author recognises that it would have been desirable to use regression methods in preference to a series of correlations, but the low sample size meant that the basic requirements for regression would not have been met. Even if the number of variables to investigate were substantially reduced, there would have been insufficient
numbers to carry out a regression analysis (number of participants = 50 + (10 x number of variables) Tabachnick and Fidell, 1996). A regression analysis would have avoided the need for a series of correlations and allowed for more definite conclusions to be drawn.

Furthermore, due to the number of correlational analyses, the possibility of type 1 errors was increased. If a Bonferroni correction had been utilised, many of the results would not have reached statistical significance (adjusted significance level = 0.004).

Bryman and Cramer (1994) assert that it is important to consider both the significance level and the size of the correlation coefficient in determining the importance of a correlation. Therefore, although the correlations may not be statistically significant at the adjusted level, the correlations were all low to moderate correlations which are likely to represent relationships possibly worthy of further investigation. Evidence from similar analyses with other research samples was examined and similar patterns demonstrated.

The study may have suffered from a selection bias. The women who chose to participate in the research may have been those who had lower levels of depression. It is possible that women with higher levels of depression opted out of the study at the initial stage. This raises important questions about accessing a representative population for future research studies. Accessing women who are reluctant to participate in research is a challenge but an important one in order to establish representative conclusions.

It is plausible that the scores on the HADS were influenced by social desirability, with participants underreporting symptoms of both depression and anxiety. Although the questionnaire was completed independently and privately by the participant in the majority of cases, a small number of participants requested the items to be read out and answered verbally (possibly due to problems with visibility or literacy). It is possible that participants wished to present themselves as coping well with cancer, and hence minimised any psychological difficulties.
Caution must be exercised when interpreting the results of the study. The correlational nature of the analyses means that causal relationships cannot be inferred. In retrospect, a longitudinal, prospective design would be better suited to investigating causality.

The low proportion of variance that was explained by the correlations suggest the presence of other confounding variables. Other confounding variables have been also suggested to be related to psychological adjustment. Schnoll, Harlow, Stolbach and Brandt (1998) assert that anxiety and depression are significantly reduced when individuals received adequate emotional and functional support. Age has been suggested to be another possible confounding factor. Wellisch (1987, cited by Welch-McCaffrey et al, 1989) commented that older survivors are more likely to experience physical compromise such as exhaustion, during the early part of their illness and recovery, and less likely to have psychological problems. Conversely, younger patients may initially experience more psychological problems with less physical distress.

Uncertainty remains about the representativeness of the sample in the study. This study cannot claim to be a representative sample of women survivors of breast cancer. The socio-economic status of those who chose not to participate in the study is not known neither are race and cultural details. Much research in this area has had similar bias with samples often drawn from white, middle class women. Illness perceptions have been found to differ across cultures (Sissons Joshi, 1995, cited by Hampson, 1997), and therefore different cultures and ethnic backgrounds may well hold different illness perceptions of breast cancer.

Conclusions

Methodological limitations aside, this study makes new contributions to the current literature. It supports the expanding research indicating the role that illness perceptions play in understanding adjustment to disease and illness. Illness perceptions were shown to be related to anxiety. The coping styles adopted did not show any relationship to anxiety or depression. The self-regulatory model hypothesises that coping mediates
psychological adjustment. The results from this study indicate that illness perceptions may directly influence psychological adjustment, or vice versa, and may be a better predictor of psychological adjustment than coping style. Findings from research in other illness conditions confirms this conclusion, however further research is necessary to establish a causal link between illness perceptions and psychological adjustment.

Furthermore, the clinical relevance of the study has been illustrated, both in terms of recognising the psychosocial consequences of surviving breast cancer, and the possibility of using the illness perceptions structure to work therapeutically with survivors.
References


risk of recurrence compared with the general population: a valid comparison? *Journal of Clinical Epidemiology*, **52**, 523-530.


Appendix One

Letter of approval from ethics committee

East Surrey Hospital Clinical Research
Ethics Sub Committee

Chair: Dr F Matthey, FRCP, FRCPath
Consultant Clinical Haematologist

Tel: Secretary - 01737 768511 ext 8309
Consultant - 01737 782991 (Direct Line)
Fax: 01737 782942

Our Ref FM/sjr
Your Ref

15 September 1999

Ms C Graham
Clinical Psychologist in Training
Clinical Psychology Department
University of Guildford
GUILDFORD
GU2 5XH

Dear Ms Graham

Re: Application 2291 — The relationship between illness perceptions, coping styles and psychological well being in women surviving breast cancer

The East Surrey Hospital Local Research Ethics Sub-Committee met on Friday 3 September 1999. At this meeting the full Committee considered your amendments to the above study.

The members were pleased to give your study full approval following receipt of the amendments.

Please be aware, however, that in common with all approved research studies you are required to:

- Submit any further protocol amendments to the Ethics Sub-Committee without delay.
- Inform the Ethics Sub-Committee when the trial has been completed.
- You may also be asked to give a brief update in the progress of this study.

Yours sincerely

Dr F Matthey
Chairman – ESHCRES-C

Research dossier: Major Research Project
Appendix Two

Research Correspondence: G.P. letter.

Dear Dr .....................,

Re ..............................................

We are writing to inform you of our intention to contact the above patient to take part in a research project. The research project is examining women's perceptions of their breast cancer, how they cope with it and their psychological well-being.

If she agrees to participate in the study, she will be interviewed about her experience of breast cancer. She will also be asked to fill in some questionnaires. It is anticipated that the interview will take about an hour.

If you know of any reason why we should not contact this patient to ask them to participate, please let us know as soon as possible. You can reach us on ....... If we do not hear from you within two weeks, we shall assume that we can go ahead and write to her.

Thank you very much for your assistance,

Yours sincerely,

Carolyn Graham
Clinical psychologist in training

Trust Headquarters
East Surrey Hospital
Canada Avenue
Redhill
Surrey
RH1 5RH
Tel: 01737 768511
Dear,

We are writing to request your participation in a research project. We are writing to some women who have had treatment for breast cancer at Crawley and East Surrey Hospitals. I am a clinical psychologist in training at the University of Surrey with a particular interest in women’s experiences of breast cancer.

We are aiming to improve the understanding of health care professionals about breast cancer and would like to find out about its impact on women’s lives, and the ways that women cope with the illness.

To do this, we would like to meet with you to ask you some questions. This may take about an hour of your time. The answers that you give will help us to understand more about what breast cancer means to women who have had the illness, and the impact it has on their lives. The information sheet enclosed explains the interview in more detail.

If you are willing to take part in the study, please fill out the reply slip on the next page and post it in the stamped addressed envelope enclosed.

If you decide not to participate in the project it will not affect any future care or treatment you receive as a patient of the service.

Thank you for taking the time to read this letter and helping us with our research. We appreciate your help very much. If you would like any further information, please contact us at the above address.

Yours sincerely,

Carolyn Graham
Clinical psychologist in training

Clinical psychologist
Information Sheet

The Breast Care Service, as well as improving physical care, is interested in ways to improve psychological care. As part of this process, we want to interview women who have had breast cancer, to find out about their experiences.

The interview
This will take approximately an hour of your time. You will be asked to fill out some questionnaires and to answer some questions about your experience of breast cancer. You do not have to answer any questions that you do not wish to. The questionnaires will let us know how you see yourself, and about how you see your illness. The interviewer will also ask you about things you do to help you cope with your illness.

Information from interviews
The information collected from the interview will be completely anonymous. Your name will not be kept in our research records, and will not be included on the questionnaires.

The information will help us to understand more about women’s experiences of breast cancer, and ways we can help.

If you are willing to take part please fill in the slip below and post it to us in the stamped addressed envelope provided. If you would like more information about this study, please contact us on . We will be happy to answer any questions you have.

If you do not wish to take part in the study it will not affect any future care or treatment you receive as a patient.

I am willing to be contacted about taking part in the study

Name: ___________________________ Signed: ___________________________

Telephone number: ___________________________

Address: ___________________________

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### Appendix Three

#### Research Questionnaires: Hospital Anxiety and Depression Scale (HADS)

This questionnaire is designed to look at how you feel. Read each item and tick the reply which comes closest to how you have been feeling in the past week. Please tick one box only.

Don’t take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought out response. Please answer all the statements from 1-14.

If you are in any doubt, please tick the box which is closest to how you feel.

<table>
<thead>
<tr>
<th>Item</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>I feel tense or ‘wound up’</strong></td>
<td></td>
</tr>
<tr>
<td>Most of the time</td>
<td>☐</td>
</tr>
<tr>
<td>A lot of the time</td>
<td>☐</td>
</tr>
<tr>
<td>From time to time, occasionally</td>
<td>☐</td>
</tr>
<tr>
<td>Not at all</td>
<td>☐</td>
</tr>
<tr>
<td><strong>I still enjoy the things I used to enjoy:</strong></td>
<td></td>
</tr>
<tr>
<td>Definitely as much</td>
<td>☐</td>
</tr>
<tr>
<td>Not quite so much</td>
<td>☐</td>
</tr>
<tr>
<td>Only a little</td>
<td>☐</td>
</tr>
<tr>
<td>Hardly at all</td>
<td>☐</td>
</tr>
<tr>
<td><strong>I get a sort of frightened feeling as if something awful is about to happen:</strong></td>
<td></td>
</tr>
<tr>
<td>Very definitely and quite badly</td>
<td>☐</td>
</tr>
<tr>
<td>Yes, but not too badly</td>
<td>☐</td>
</tr>
<tr>
<td>A little, but it doesn’t bother me</td>
<td>☐</td>
</tr>
<tr>
<td>Not at all</td>
<td>☐</td>
</tr>
<tr>
<td><strong>I can laugh and see the funny side of things:</strong></td>
<td></td>
</tr>
<tr>
<td>As much as I always could</td>
<td>☐</td>
</tr>
<tr>
<td>Not quite so much now</td>
<td>☐</td>
</tr>
<tr>
<td>Definitely not so much now</td>
<td>☐</td>
</tr>
<tr>
<td>Not at all</td>
<td>☐</td>
</tr>
<tr>
<td><strong>Worrying thoughts go through my mind:</strong></td>
<td></td>
</tr>
<tr>
<td>A great deal of the time</td>
<td>☐</td>
</tr>
<tr>
<td>A lot of the time</td>
<td>☐</td>
</tr>
<tr>
<td>From time to time but not often</td>
<td>☐</td>
</tr>
<tr>
<td>Only occasionally</td>
<td>☐</td>
</tr>
<tr>
<td><strong>I feel cheerful:</strong></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>☐</td>
</tr>
<tr>
<td>Not often</td>
<td>☐</td>
</tr>
<tr>
<td>Sometimes</td>
<td>☐</td>
</tr>
<tr>
<td>Most of the time</td>
<td>☐</td>
</tr>
<tr>
<td><strong>I feel restless as if I have to be on the move:</strong></td>
<td></td>
</tr>
<tr>
<td>Very much indeed</td>
<td>☐</td>
</tr>
<tr>
<td>Quite a lot</td>
<td>☐</td>
</tr>
<tr>
<td>Not very much</td>
<td>☐</td>
</tr>
<tr>
<td>Not at all</td>
<td>☐</td>
</tr>
<tr>
<td><strong>I look forward with enjoyment to things:</strong></td>
<td></td>
</tr>
<tr>
<td>As much as I ever did</td>
<td>☐</td>
</tr>
<tr>
<td>Rather less than I used to</td>
<td>☐</td>
</tr>
<tr>
<td>Definitely less than I used to</td>
<td>☐</td>
</tr>
<tr>
<td>Hardly at all</td>
<td>☐</td>
</tr>
<tr>
<td><strong>I get sudden feelings of panic:</strong></td>
<td></td>
</tr>
<tr>
<td>Very often indeed</td>
<td>☐</td>
</tr>
<tr>
<td>Quite often</td>
<td>☐</td>
</tr>
<tr>
<td>Not very often</td>
<td>☐</td>
</tr>
<tr>
<td>Not at all</td>
<td>☐</td>
</tr>
<tr>
<td><strong>I can enjoy a good book or radio or tv programme:</strong></td>
<td></td>
</tr>
<tr>
<td>Often</td>
<td>☐</td>
</tr>
<tr>
<td>Sometimes</td>
<td>☐</td>
</tr>
<tr>
<td>Not often</td>
<td>☐</td>
</tr>
<tr>
<td>Very seldom</td>
<td>☐</td>
</tr>
</tbody>
</table>

Please check that you have answered all the statements.
## Appendix Three (Continued)

### Research Questionnaires: Illness Perceptions Questionnaire

**YOUR VIEWS ABOUT YOUR ILLNESS**

Listed below are a number of symptoms that you may or may not have experienced since your illness. Please indicate by circling Yes or No, whether you have experienced any of these symptoms since your illness, and whether you believe that these symptoms are related to your illness.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Yes</th>
<th>No</th>
<th>Related to Illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sleep difficulties</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skin changes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hard or tender growths in the body</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breathlessness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nausea</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stiffness or tenderness in the body</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weight changes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Irritability</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nervousness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Upset stomach</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Fatigue</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficulty concentrating</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Hot flashes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Headaches</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

We are interested in your own personal views of how you now see your current illness.

Please indicate how much you agree or disagree with the following statements about your illness by indicating your choice on the following scale:

**VIEW ABOUT YOUR ILLNESS**

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neither Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>A germ or virus caused my illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diet played a major role in causing my illness</td>
<td></td>
<td></td>
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<tr>
<td>Pollution of the environment caused my illness</td>
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<tr>
<td>My illness is hereditary - it runs in my family</td>
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<tr>
<td>It was just by chance that I became ill</td>
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<tr>
<td>Stress was a major factor in causing my illness</td>
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<tr>
<td>My illness is largely due to my own behaviour</td>
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<tr>
<td>Other people played a large role in causing my illness</td>
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<td></td>
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</tr>
<tr>
<td>My illness was caused by poor medical care in the past</td>
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<td></td>
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<tr>
<td>My state of mind played a major part in causing</td>
<td></td>
<td></td>
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</tbody>
</table>
I.P.Q

YOUR VIEWS ABOUT YOUR ILLNESS
(Continued)

<table>
<thead>
<tr>
<th>VIEWS ABOUT YOUR ILLNESS</th>
<th>STRONGLY AGREE</th>
<th>AGREE</th>
<th>NEITHER AGREE NOR DISAGREE</th>
<th>DISAGREE</th>
<th>STRONGLY DISAGREE</th>
</tr>
</thead>
<tbody>
<tr>
<td>My illness will last a short time</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>My illness is likely to be permanent rather than temporary</td>
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<tr>
<td>My illness will last for a long time</td>
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<tr>
<td>My illness is a serious condition</td>
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<tr>
<td>My illness has had major consequences on my life</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>My illness has become easier to live with</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My illness has not had much effect on my life</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>My illness has strongly affected the way others see me</td>
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<td></td>
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<tr>
<td>My illness has serious economic and financial consequences</td>
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<tr>
<td>My illness has strongly affected the way I see myself as a person</td>
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<tr>
<td>My illness will improve in time</td>
<td></td>
<td></td>
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<tr>
<td>There is a lot which I can do to control my symptoms</td>
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</tr>
<tr>
<td>There is very little that can be done to improve my illness</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>My treatment will be effective in curing my illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recovery from my illness is largely dependent on chance or fate</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>What I do can determine whether my illness gets better or worse</td>
<td></td>
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<td></td>
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</tr>
</tbody>
</table>
Appendix Three (Continued)

Research Questionnaires: COPE

COPE

<table>
<thead>
<tr>
<th>Name:</th>
<th>Date:</th>
<th>Record Number:</th>
</tr>
</thead>
</table>

We are interested in how people respond when they confront difficult or stressful events in their lives. There are lots of ways to try to deal with stress. This questionnaire asks you to indicate what you generally do and feel when you experience stressful events. Obviously, different events bring out somewhat different responses, but think about what you usually do when you are under a lot of stress.

Then respond to each of the following items by choosing one number for each, using the response choices listed just below.

1 = I usually don’t do this at all.  
2 = I usually do this a little bit.  
3 = I usually do this a medium amount.  
4 = I usually do this a lot.

Please try to respond to each item separately in your mind from each other item. Choose your answers thoughtfully, and make your answers as true FOR YOU as you can. Please answer every item. There are no ‘right’ or ‘wrong’ answers, so choose the most accurate answer for YOU – not what you think ‘most people’ would say or do. Indicate what YOU usually do when YOU experience a stressful event.

<table>
<thead>
<tr>
<th>Item</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I try to grow as a person as a result of the experience.</td>
<td></td>
</tr>
<tr>
<td>2. I turn to work or other substitute activities to take my mind off things.</td>
<td></td>
</tr>
<tr>
<td>3. I get upset and let my emotions out.</td>
<td></td>
</tr>
<tr>
<td>4. I try to get advice from someone about what to do.</td>
<td></td>
</tr>
<tr>
<td>5. I concentrate my efforts on doing something about it.</td>
<td></td>
</tr>
<tr>
<td>6. I say to myself “this isn’t real”.</td>
<td></td>
</tr>
<tr>
<td>7. I put my trust in God.</td>
<td></td>
</tr>
<tr>
<td>8. I laugh about the situation.</td>
<td></td>
</tr>
<tr>
<td>9. I admit to myself that I can’t deal with it, and give up trying.</td>
<td></td>
</tr>
<tr>
<td>10. I restrain myself from doing anything too quickly.</td>
<td></td>
</tr>
<tr>
<td>11. I discuss my feelings with someone.</td>
<td></td>
</tr>
<tr>
<td>12. I use alcohol or drugs to make myself feel better.</td>
<td></td>
</tr>
<tr>
<td>13. I get used to the idea that it happened.</td>
<td></td>
</tr>
<tr>
<td>14. I talk to someone to find out more about the situation.</td>
<td></td>
</tr>
<tr>
<td>15. I keep myself from getting distracted by other thoughts or activities.</td>
<td></td>
</tr>
<tr>
<td>16. I daydream about things other than this.</td>
<td></td>
</tr>
<tr>
<td>17. I get upset, and am really aware of it.</td>
<td></td>
</tr>
<tr>
<td>18. I seek God’s help.</td>
<td></td>
</tr>
<tr>
<td>19. I make a plan of action.</td>
<td></td>
</tr>
<tr>
<td>20. I make jokes about it.</td>
<td></td>
</tr>
<tr>
<td>Number</td>
<td>Description</td>
</tr>
<tr>
<td>--------</td>
<td>-------------</td>
</tr>
<tr>
<td>21</td>
<td>I accept that this has happened and that it can't be changed.</td>
</tr>
<tr>
<td>22</td>
<td>I hold off doing anything about it until the situation permits.</td>
</tr>
<tr>
<td>23</td>
<td>I try to get emotional support from friends and relatives.</td>
</tr>
<tr>
<td>24</td>
<td>I just give up trying to reach my goal.</td>
</tr>
<tr>
<td>25</td>
<td>I take additional action to try to get rid of the problem.</td>
</tr>
<tr>
<td>26</td>
<td>I try to lose myself for a while by drinking alcohol or taking drugs.</td>
</tr>
<tr>
<td>27</td>
<td>I refuse to believe that it has happened.</td>
</tr>
<tr>
<td>28</td>
<td>I let my feelings out.</td>
</tr>
<tr>
<td>29</td>
<td>I try to see it in a different light, to make it seem more positive.</td>
</tr>
<tr>
<td>30</td>
<td>I talk to someone who could do something concrete about the problem.</td>
</tr>
<tr>
<td>31</td>
<td>I sleep more than usual.</td>
</tr>
<tr>
<td>32</td>
<td>I try to come up with a strategy about what to do.</td>
</tr>
<tr>
<td>33</td>
<td>I focus on dealing with this problem and, if necessary, let other things slide a little.</td>
</tr>
<tr>
<td>34</td>
<td>I get sympathy and understanding from someone.</td>
</tr>
<tr>
<td>35</td>
<td>I drink alcohol or take drugs, in order to think about it less.</td>
</tr>
<tr>
<td>36</td>
<td>I kid around about it.</td>
</tr>
<tr>
<td>37</td>
<td>I give up the attempt to get what I want.</td>
</tr>
<tr>
<td>38</td>
<td>I look for something good in what is happening.</td>
</tr>
<tr>
<td>39</td>
<td>I think about how I might best handle the problem.</td>
</tr>
<tr>
<td>40</td>
<td>I pretend that it hasn't really happened.</td>
</tr>
<tr>
<td>41</td>
<td>I make sure not to make matters worse by acting too soon.</td>
</tr>
<tr>
<td>42</td>
<td>I try hard to prevent other things from interfering with my efforts at dealing with this.</td>
</tr>
<tr>
<td>43</td>
<td>I go to the cinema or watch television, to think about it less.</td>
</tr>
<tr>
<td>44</td>
<td>I accept the reality of the fact that it happened.</td>
</tr>
<tr>
<td>45</td>
<td>I ask people who have had similar experiences what they did.</td>
</tr>
<tr>
<td>46</td>
<td>I feel a lot of emotional distress and I find myself expressing these feelings a lot.</td>
</tr>
<tr>
<td>47</td>
<td>I take direct action to get around the problem.</td>
</tr>
<tr>
<td>48</td>
<td>I try to find comfort in my religion.</td>
</tr>
<tr>
<td>49</td>
<td>I force myself to wait for the right time to do something.</td>
</tr>
<tr>
<td>50</td>
<td>I make fun of the situation.</td>
</tr>
<tr>
<td>51</td>
<td>I reduce the amount of effort I'm putting into solving the problem.</td>
</tr>
<tr>
<td>52</td>
<td>I talk to someone about how I feel.</td>
</tr>
<tr>
<td>53</td>
<td>I use alcohol or drugs to help me get through it.</td>
</tr>
<tr>
<td>54</td>
<td>I learn to live with it.</td>
</tr>
<tr>
<td>55</td>
<td>I put aside other activities in order to concentrate on this.</td>
</tr>
<tr>
<td>56</td>
<td>I think hard about what steps to take.</td>
</tr>
<tr>
<td>57</td>
<td>I act as though it hasn't even happened.</td>
</tr>
<tr>
<td>58</td>
<td>I do what has to be done, one step at a time.</td>
</tr>
<tr>
<td>59</td>
<td>I learn something from the experience.</td>
</tr>
<tr>
<td>60</td>
<td>I pray more than usual.</td>
</tr>
</tbody>
</table>


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Code 4920 04 4
Appendix Three (Continued)
Research Questionnaires: Interview Schedule

Interview Schedule

Code: ____________ Date of Interview: ____________

Age: ____________ Occupation: ____________

Dependents: ____________ Marital Status: ____________

History of the disease

Perhaps the best way to begin is to find out how this started.

Approximate time of diagnosis:

How was it that the lump was found?

a) who found the lump
b) delay in seeing doctor. Why
c) Did you think it was cancer
d) Why or why not
Treatment:  Surgery  
Chemotherapy  
Radiotherapy  

Dates

What was your reaction to partial or total loss of breast?

Physical adjustment to surgery / chemotherapy / radiotherapy?

Next follow up:

What symptoms were you having from the disease before diagnosis?

What symptoms did you experience during treatment?

Are you experiencing any symptoms currently that you think are related to the disease?
Many people who have had cancer develop some sort of theory about how they got cancer. In other words, although we don’t know all of the causes of cancer, not people have some hunch or theory why they have it. I wonder if you would wind sharing your hunch or theory with me, if you have any.

Do you think that the course of your cancer is something that you have control over?

Do you think the course of your cancer is something that can be controlled by someone else or something other than you?

Please list the changes that have occurred in your life since having cancer and when each occurred?

Changes in
Diet
Smoking
Medications
Alcohol consumption
Exercise pattern
<table>
<thead>
<tr>
<th>Ways of coping with day to day stress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Work time</td>
</tr>
<tr>
<td>Leisure time</td>
</tr>
<tr>
<td>Religion</td>
</tr>
<tr>
<td>New activities</td>
</tr>
</tbody>
</table>

Do you view the changes as positive or negative?

How often do you think about the possibility of the cancer coming back?

1 Not at all  
4 A lot of the time

How do you control the worry / cope with this threat?
### Appendix Four (Continued)

**Verbatim responses to open ended questions: Consequences**

**Responses arranged by category**

<table>
<thead>
<tr>
<th>Diet</th>
<th>8</th>
<th>Sexuality/ body Image</th>
<th>7</th>
<th>Physical Changes</th>
<th>8</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;I try hard to eat healthily&quot;</td>
<td></td>
<td>&quot;Lost interest in sex due to surgery and tamoxifen. Don't feel whole. Still bothers me now. Very shy about it&quot;</td>
<td></td>
<td>&quot;Lost appetite and taste&quot;</td>
<td></td>
</tr>
<tr>
<td>&quot;Changes in food. Ways to protect from cancer. I eat pulses and soya beans - cut out dairy produce&quot;</td>
<td></td>
<td>&quot;Loss of interest in sex. I used to bathe in the dark with candles so I couldn't see it&quot;</td>
<td></td>
<td>&quot;Tamoxifen has caused cataracts, dermatitus and hair loss. I'm more tired&quot;</td>
<td></td>
</tr>
<tr>
<td>&quot;Eat organically, gave up coffee&quot;</td>
<td></td>
<td>&quot;Losing femininity&quot;</td>
<td></td>
<td>&quot;Changes in my health&quot;</td>
<td></td>
</tr>
<tr>
<td>&quot;Eating more fruit and vegetables&quot;</td>
<td></td>
<td>&quot;Body image and being more self conscious&quot;</td>
<td></td>
<td>&quot;Pain&quot;</td>
<td></td>
</tr>
<tr>
<td>&quot;Eat less red meat and cut down on alcohol&quot;</td>
<td></td>
<td>&quot;Sometimes when I undress and look in the mirror I catch sight of it&quot;</td>
<td></td>
<td>&quot;Losing youth due to the menopause&quot;</td>
<td></td>
</tr>
<tr>
<td>&quot;Organic vegetables and become a vegan&quot;</td>
<td></td>
<td>&quot;Conscious of what I wear&quot;</td>
<td></td>
<td>&quot;Tired&quot;</td>
<td></td>
</tr>
<tr>
<td>&quot;Increased fruit and vegetables&quot;</td>
<td></td>
<td>&quot;I felt like a freak&quot;</td>
<td></td>
<td>&quot;Still sore from my reconstruction. Implant feels bulked out&quot;</td>
<td></td>
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<tr>
<td>&quot;Watch what I eat&quot;</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>Increase in Fitness / Health</td>
<td>8</td>
<td></td>
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<tr>
<td>&quot;Losing weight. I'm fitter than ever&quot;</td>
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<tr>
<td>&quot;Took vitamins to build up my immune system&quot;</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&quot;more healthy life style, diet and exercise&quot;</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>&quot;Cut down on smoking&quot;</td>
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<tr>
<td>&quot;Lost weight. Exercise more, use the bike and walk&quot;</td>
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<tr>
<td>&quot;Do lots of exercise&quot;</td>
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<tr>
<td>&quot;More exercise - bought a dog&quot;</td>
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<tr>
<td>&quot;Given up smoking&quot;</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Better at dealing with stress</td>
<td>8</td>
<td>Worse at dealing with stress</td>
<td>3</td>
<td></td>
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<td>--------------------------------</td>
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<td>-------------------------------</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>&quot;Deal with stress differently.&quot;</td>
<td>8</td>
<td>&quot;Sometimes I get more stressed&quot;</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&quot;Try not to get stressed and get into my old ways&quot;</td>
<td>8</td>
<td>&quot;I get more uptight than I used to&quot;</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&quot;I'm better at recognising stress.&quot;</td>
<td>8</td>
<td>&quot;Now cope with stress by blowing up&quot;</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&quot;Don't rise to everyone. Let it all go over my head&quot;</td>
<td>8</td>
<td></td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&quot;Ways of coping with day to day stress is better. Can relate trivial things to having cancer&quot;</td>
<td>8</td>
<td></td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&quot;Have calmed down. Not so hett up and irritable&quot;</td>
<td>8</td>
<td></td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&quot;Don't worry as much&quot;</td>
<td>8</td>
<td></td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&quot;More focused and calm&quot;</td>
<td>8</td>
<td></td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Career change / more enjoyable job</td>
<td>3</td>
<td>Cut down work / unable to work</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&quot;better job and full time&quot;. &quot;Learning to be reflexologist&quot; &quot;Doing things I enjoy. Helping with gardening&quot;.</td>
<td>3</td>
<td>&quot;Went back to work but I could not settle. Gave it up&quot;</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working time reduced</td>
<td>3</td>
<td>Restricted activity</td>
<td>7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&quot;Around more for the family&quot;</td>
<td>7</td>
<td>&quot;Gardening restricted due to infections&quot;</td>
<td>7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&quot;Cut down on work. More conscious of making time&quot;</td>
<td>7</td>
<td>&quot;Can do less&quot;</td>
<td>7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&quot;Cut down on working time. Enjoy having more time to myself&quot;.</td>
<td>7</td>
<td>&quot;Can't do as much exercise&quot;</td>
<td>7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Increased assertion / self value</td>
<td>3</td>
<td>Mood changes</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&quot;Now I've got more self worth and self value. I'm the first in the queue. Not frightened of saying no&quot;.</td>
<td>4</td>
<td>&quot;I get tearful and panic a lot&quot;</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>&quot;More tearful with day to day stresses&quot;</td>
<td>4</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
"I'm prepared to say no more often to people who ask me things."
"I delegate more things now"

<table>
<thead>
<tr>
<th>New activities</th>
<th>4</th>
<th>Relationships/Other people</th>
</tr>
</thead>
</table>
| "Taken up yoga" |   | "Family paranoid. Treat me like china."
| "Church and religion" |   | "Not as gregarious as I was...Avoid meeting new people". |
| "Write poetry" |   |                             |
| "sculpture and painting" |   |                             |

"More irritable"
"Mood"
### Appendix Four (continued)

Verbatim responses to open ended questions: Control / cure

Responses arranged by category

<table>
<thead>
<tr>
<th>Response</th>
<th>Verbatim Responses</th>
<th>Frequency</th>
</tr>
</thead>
</table>
| Positive thinking / attitude | "The way you think could affect cancer. Trying not to think about it makes it better. If you spend time thinking about it, it will come back."  
"You can control cancer by positive thinking. It won't beat me. I'm doing everything in my power. My mind is powerful."  
"Attitudes make a big difference. Some people frighten themselves to death"  
"Positive thinking - a belief you will get over it. Helps with the recovery process"  
"Can control it as part of a combination of circumstances. Husband died because he had nothing to live for"  
"Control cancer with a positive attitude"  
"(control by building up body) and a positive attitude" | 7         |
| Removing stress           | "Can control cancer by removing stress from your life. Mind over matter - not getting myself into a stressed state. If I went back to my old job it would all come back."  
"Friend had turbulent love life which made her situation worse."  
"Can control cancer in some ways if it's stress related". | 3         |
| Diet                      | "Can protect self from cancer by avoiding certain foods."  
"Eat organic fruit and vegetables. It's a cushion between me and it coming back" | 2         |
<p>| Hormone therapy           | &quot;If you're on tablets - they prevent cancer, but you can still get it&quot;. | 1         |
| Alternative therapies     | &quot;I'm into alternatives&quot; | 1         |
| Increased fitness         | &quot;Control by building up body.&quot; | 1         |</p>
<table>
<thead>
<tr>
<th>Diet</th>
<th>&quot;Can protect self from cancer by avoiding certain foods.&quot;</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>&quot;Eat organic fruit and vegetables. It's a cushion between me and it coming back.&quot;</td>
</tr>
</tbody>
</table>
### Appendix Four (continued)

Verbatim responses to open ended questions: Cause

Responses arranged by category

<table>
<thead>
<tr>
<th>Theories / hunches</th>
<th>Illustrative examples</th>
<th>Frequency</th>
</tr>
</thead>
</table>
| Stress / Life events     | "I had a very stressful life. I had to be the stronger partner. I’m not surprised I got cancer. In the ward all the ladies I spoke to had stressful lives".  
"Stress. My son left his wife and my husband got epilepsy and my youngest son became alcoholic. I had to be the stronger partner. That makes you more stressed. I’m not surprised I got cancer. In the ward all the ladies I spoke to had stressful lives".  
"The surgeon reckoned it had been growing for a year. During that year my husband was made redundant, I was unhappy and my son was ill".  
"Stress and unnecessary worrying. I lost my parents in the gas chambers and had an alcoholic husband. I’ve led a very stressed life".  
"I was stressed out".  
"Stress. I bought a home and had a lot to worry about".  
"Stressful life, divorce and trauma".  
"Stress - great part of it. Cancer is something in us and different things bring it on".  
"Stress, being divorced".  
"Stress".  
"Anxiety and stress. The family".  
"Stress".  
"Stress".  
"Stress and changes in life".  
"Traumatic high stress life". | 15        |
| Injury / Trauma to breast | "My grandson hit me with a toy on my breast in the same place."  
"Maybe honks and falls. My dog got knocked down and within a year he got leukaemia"  
"Fall from the loft. Hurt my back and sides".  
"My daughter fell and hit against my breast - very painful".  
"Knocked in the chest in the garden" | 8         |
<table>
<thead>
<tr>
<th>Research dossier: Major Research Project</th>
</tr>
</thead>
</table>

| Injury / Trauma to breast | "My grandson hit me with a toy on my breast in the same place."
|                           | "Maybe bonks and falls. My dog got knocked down and within a year he got leukaemia"
|                           | "Fall from the loft. Hurt my back and sides"
|                           | "My daughter fell and hit against my breast - very painful"
|                           | "Knocked in the chest in the garden"
|                           | "Injury to the breast"
|                           | "Maybe bonks and falls. Dog got knocked down and within a year he was dead with leukaemia"
|                           | "Cutting down a tree and hit my breast"

| Genetic / Hereditary Factors | "Once I was diagnosed aware that grandmother and aunt had breast cancer but were shy of talking about it. It's possibly hereditary"
|                            | "Runs in the family"
|                            | "(menopause and ) hereditary causes"
|                            | "Genetic - sister and aunt"
|                            | "Could run in the family"
|                            | "Family. Sister had ovarian cancer, aunt and cousin died of breast cancer"
|                            | "Mother had lung cancer"

| Lifestyle and Personal Choice e.g. Diet, job, smoking | "It's caused by milk left in the nipple whilst breast feeding"
|                                                      | "Altitude. Used to be long haul stewardess"
|                                                      | "Not looking after your self"
|                                                      | "I smoked when I was diagnosed"
|                                                      | "Being tired. I opened myself up to getting cancer"
|                                                      | "Diet"

| Environmental Hazards | "Geophysical stress- a river runs underneath my old work. Four people are off long term with cancer"
|                       | "The airport. Three of us neighbours have cancer. Dumping fuel into the atmosphere"
|                       | "The environment, what you're eating and breathing"
|                       | "Under the flight path. Shoot out fuel when they land. I've found fuel in the garden"
| Hormones / menopause | "Had bad headaches as a teenager. I took hormone tablets. I wondered if this might cause it"  
|                      | "Hormone replacement therapy or menopause"  
|                      | "Hormones"  
|                      | "Menopause (and hereditary causes)"  
|                      | "HRT"  
|                      | "No children" | 6 |
| Psychological factors/ own characteristics | "Life has always been about caring and giving. I've given too much. I was not a strong person."  
|                      | "I used to think I wished it on myself. Used to hear about people who had cancer. I wonder if I wished it on. That played on my mind." | 2 |
| Fate / Luck / chance | "Bad luck and chance"  
|                      | "It's fate. It's just something that happens."  
|                      | "Fate. It's just one of those things" | 3 |
| Other theories | "Pain causes cancer. I had mammogram for cysts. It was painful then I got cancer"  
|                      | "Reincarnation - It's punishment for a former life" | 1 |
Appendix Four (continued)

Verbatim responses to open ended questions: Coping with fears of recurrence

Responses arranged by category

<table>
<thead>
<tr>
<th>Coping strategy</th>
<th>Illustrative Examples</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive strategies</td>
<td>&quot;I try not to think about it&quot;</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>&quot;Cope by trying to occupy myself&quot;</td>
<td></td>
</tr>
<tr>
<td></td>
<td>&quot;Try not to think about it. Do something else&quot;</td>
<td></td>
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<tr>
<td></td>
<td>&quot;Try and put it to the back of my mind. Think positive thoughts like I'm not going to let this beat me&quot;</td>
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<td></td>
<td>&quot;Going out for a walk helps, doing something different&quot;</td>
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<tr>
<td></td>
<td>&quot;Control the worry by being occupied&quot;</td>
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<tr>
<td></td>
<td>&quot;Put a mental block down&quot;</td>
<td></td>
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<tr>
<td></td>
<td>&quot;Something reminds me, it comes into my mind. It goes away if occupied. I cope by distraction&quot;</td>
<td></td>
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<tr>
<td></td>
<td>&quot;Try not to think about it. Worry won't change anything&quot;</td>
<td></td>
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<tr>
<td></td>
<td>&quot;Shouldn't dwell upon it. I busy myself&quot;</td>
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<tr>
<td></td>
<td>&quot;At the back of my mind, I try not to dwell on it. If I dwell on it I feel down&quot;</td>
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<tr>
<td></td>
<td>&quot;I take my mind of it - say don't be stupid&quot;</td>
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<tr>
<td></td>
<td>&quot;I don't allow myself to think about the possibility of it coming back&quot;</td>
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</tr>
<tr>
<td></td>
<td>&quot;Try to push it out of my mind&quot;</td>
<td></td>
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<tr>
<td></td>
<td>&quot;I tend to concentrate on working harder - put it to the back of my mind.&quot;</td>
<td></td>
</tr>
<tr>
<td></td>
<td>&quot;Positive thinking&quot;</td>
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</tr>
<tr>
<td>Vigilance / checking</td>
<td>&quot;Examine self once a week. Think if I can't feel any lumps I must be alright&quot;</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>&quot;Pay more attention to feelings in my body&quot;</td>
<td></td>
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<tr>
<td></td>
<td>&quot;If I get an ache in a joint I worry it's more cancer. If a pain carries on for a day or two may get help&quot;</td>
<td></td>
</tr>
<tr>
<td>Research dossier: Major Research Project</td>
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<tr>
<td>-----------------------------------------</td>
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</tbody>
</table>

| Time | "I've been a pest to the doctor, nearly every day...prompted by physical sensations" |
|      | "If I get an ache or a pain - if the ache goes, I've been stupid. I check myself about 5 times a week" |
|      | "rely on the fact that I would know the symptoms" |
| Put it behind / carry on with life | "I've had cancer. It's in the past. I hope I don't get it again but I'm not letting life control that" |
|      | "You could stop living, think my life is horrendous, lonely wouldn't go anywhere, I'd rather die and be happy" |
|      | "I just carry on" |
|      | "Much more into what's happening now to make sure I live life in case it does" |
|      | "I carry on with life" |
| Fate | "If it comes back it will. I can't like forever" |
|      | "If it comes back, it comes back." |
|      | "I'm fairly fatalistic. I can't avoid it" |
| Gather evidence | "I did lots of reading - looked at the research and the statistics. Talked to friends who had it and they're ok" |
| Religion / faith | "I've got the Lord on my side. He will help me through" |
|      | "Faith ultimately helps" |
| Planning for future | "Put papers in order, investments" |
|      | "I need to be realistic about it. I have children of 11 and 7...Made plans to deal realistically with death" |
### Appendix Five

#### Summary of Correlations Conducted

**Pearson’s Correlation of age with anxiety and depression**

<table>
<thead>
<tr>
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<th>Depression</th>
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<td>Correlation co-efficient</td>
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<td>Correlation co-efficient</td>
<td>p</td>
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<tr>
<td>Age</td>
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<td>.064</td>
<td>.695</td>
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</table>

**Spearman’s Rho Correlation of anxiety and depression with tumor grade, node involvement and type of surgery**

<table>
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<tr>
<th></th>
<th>Anxiety</th>
<th></th>
<th>Depression</th>
<th></th>
</tr>
</thead>
<tbody>
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<td></td>
<td>Correlation co-efficient</td>
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<td>Correlation co-efficient</td>
<td>p</td>
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<tr>
<td>Tumor grade</td>
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<tr>
<td>Node involvement</td>
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<td>.916</td>
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<tr>
<td>Type of surgery</td>
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<td>.143</td>
<td>.084</td>
<td>.605</td>
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</table>