An Exploration of the Impact of Chronic Fatigue Syndrome and Implications for Psychological Service Provision.

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Abstract

Modern medical systems are changing to integrate a wider range of health professionals who can work together to manage total patient care. Health care is becoming increasingly based on the biopsychosocial model and incorporating greater focus on the psychological as well as the physical health of the patient. These changes in health care systems mean a larger role for psychologists and counsellors in the provision of holistic patient care. In the past, patients suffering from chronic illness received mostly biomedical interventions in their treatment programs. Increasingly however, patients with chronic illnesses who present to the medical community are referred for counselling and psychological treatment. This study focused on one chronic illness: Chronic Fatigue Syndrome (CFS). The study examined the psychological and physical impact of CFS on sufferers and on identifying which aspects of the illness impact most on patient's coping mechanisms. Seventeen participants were recruited in a randomised recruitment procedure and given a semi-structured interview that focused on key events, significant illness effects and their impact. The results demonstrated that there are particular aspects of CFS illness that can undermine and overwhelm patients' normal coping strategies and support systems. The implications for the provision of psychological services for CFS patients are discussed.

A common goal of health research is to enhance health care provider's knowledge of vulnerable populations in order to improve the quality of care provided to them (U.S. Department of Health and Human Services, 1995). For example, women's healthcare has been identified as an area underserved by the health care industry (Morse, 1995) and practitioners are advocating for holistic, biopsychosocial, cultural, and spiritual approaches to respond to women's health care needs (Wallace & Tuck, 2000). Research indicates that women's total well-being is influenced by all aspects of their lives and that women highly value engaging with health providers on a personal and sensitive level (Kettel, 1996; Morse, 1995; Trippet & Bryson, 1995). This research investigated the role and impact of counselling as part of primary care services and identified important issues for consideration when counselling individuals with chronic fatigue illnesses or other illnesses which have physical symptoms that are not externally evident. Due to the complexity of these illnesses, the external invisibility of symptoms and the fact they predominantly affect women (Donahue & Siegel, 1996) sufferers are considered to be at high risk for psychological distress.

Counselling in primary care has become increasingly prevalent during recent years (Sibbald, Addington-Hall, Brenneman, & Freeling, 1993; Thomas, 1993). Several factors have led to this increase in prevalence: increased consumer demand for counselling, increased general practitioner workload and changes to government and insurance reimbursements to include a broader range of health professionals (Harvey, Nelson, Lyons, Unwin, Monaghan, & Peters, 1998). The effectiveness of counselling in primary care has been difficult to establish empirically as the research evidence is limited and often of poor quality (Harvey et al., 1998). Major flaws in the research to date include inadequate sample sizes, high drop out rates, lack of objective assessment and poor research design. Furthermore, most studies have specifically examined particular psychotherapies rather than more generic counselling practice (see particularly Corney, 1984; Holden, Sagovsky, & Cox, 1989; Scott & Freeman, 1992; Teasdale et al., 1984; Ross & Scott, 1985). Freemantle et al. (1993) have identified the need for comprehensive evaluation of generic counselling in primary care as a research priority.

Despite the methodological weakness of many of the studies, there is evidence that supports the use of counselling as an alternative or adjunct to ongoing medical consultations (McGrath et al., 2000). One

population particularly prone to ongoing medical interventions are those who present with what is known as "Invisible Chronic Illness" that is, diseases that are characterised by chronicity and symptoms that are not externally visible to observers (Donahue & Siegel, 1996). Such illnesses are especially difficult for sufferers because; while the experience is very real and significant, the sufferer may appear externally to be physically healthy. Significant distress can occur when these individuals seek medical advice and, after exposure to a bout of diagnostic tests, are told that they are perfectly healthy and have no organic cause for their symptoms. There are numerous invisible chronic illnesses including, but not limited to Fibromyalgia, Irritable Bowel Syndrome, and Endometriosis. This research focused on Chronic Fatigue Syndrome: a debilitating and complex chronic illness.

Chronic Fatigue Syndrome: Differential Diagnosis

Chronic fatigue is one of the most perplexing conditions in the domain of medical science. Clinicians face a management path which has no "gold standard" of investigational mileposts (McGrath et al., 2000). Chronic fatigue syndrome (CFS) is comprised of a number of poorly understood signs and symptoms including chronic fatigue, cognitive impairment (memory loss, confusion, decreased concentration) and sleep disturbance (Donahue & Siegel, 1996; Natelson, 2001). Physical symptoms include swollen and painful lymph glands and headaches. Biomedical diagnosis of the syndrome is fraught with confusion. Shapiro and Moller (2002) suggest that diagnosis might depend on what is sometimes a chance referral: if pain is prominent the patient is sent to a rheumatologist and the patient is given a diagnosis of Fibromyalgia. If fatigue is most prominent the referral is to a psychiatrist and the patient is given a diagnosis of Chronic Fatigue Syndrome.

According to the CFS Association of Queensland (2002) there are no precise epidemiological figures of disease prevalence in Australia. The draft report of a Working Group, formed with the support of the Royal Australasian College of Physicians, estimated from published literature that between 0.2% and 0.7% of the population has CFS. This amounts to 36,000-126,000 Australians. By way of comparison, about 22,000 Australians have been infected with HIV and approximately 15,000 have multiple sclerosis (CFS Association of Queensland, 2002). CFS occurs frequently among adolescents and rarely among children under 10 years of age (Bell, Robinson, & Jordan, 2001) with almost 70% of sufferers being female (Wessely, 1995). The onset of CFS is typically abrupt (Friedberg & Jason, 1998). Furthermore, while the CFS Association stresses that no accurate figures are available, it estimates that 33-45% of CFS patients make a recovery whilst one-fifth to one-quarter endure the syndrome long-term.

According to the definition provided by the Centre for Disease Control in the USA (1996), Chronic Fatigue Syndrome is unexplained, persistent or relapsing fatigue which has a duration greater than six months and which is of new or definite onset (as opposed to life-long fatigue). The fatigue is not substantially alleviated by rest and results in extensive reduction in previous levels of educational, occupational, personal, or social activities. Four or more of the following symptoms must have persisted for more than six months and must not have predated the fatigue: subjective impairment in short term memory and concentration, sore throat, tender lymph nodes, muscle pain, joint pain, headaches, unrefreshing sleep and post-exertional malaise lasting longer than 24 hours (Fukuda et al., 1994). The symptoms wax and wane and as yet there is no conclusive evidence for causation. Hence, the very definition of CFS incorporates the perplexity expressed by biomedical scientists.

Fatigue is a common symptom for which patients consult their general practitioners in primary care (Jerrett, 1981). In Australia prolonged fatigue is reported by about 25% of all patients who present to general practice (Hickie et al., 1996). Unfortunately for people who are physically debilitated by CFS, 31% of doctors do not believe that CFS is a distinct syndrome and believe instead that depression is at the core of the symptomatology (Hickie et al., 1996). Because no diagnostic test can be administered to identify an organic pathogen for CFS, many doctors fall back on outdated notions of "psychosomatic diseases". This is a misdiagnosis as fewer than 5% of CFS patients meet the DSM IV diagnostic criteria for a somatisation disorder (Johnson, Deluca, & Natelson, 1996). Labels such as "psychosomatic disease" are generally interpreted by patients as "imaginary illness" and medical scepticism often drives patients to alternative forms of treatment (Lloyd et al., 2000). The diagnosis of CFS already carries with it social stigma and patients may be reluctant to pursue medical treatment if they believe they are being diagnosed as psychologically rather than physically unwell (Lehman et al., 2002). This means they may also refuse the offer of psychological services. General Practitioners may be tempted to minimise the reality of

CFS, or may mis-attribute it to psychological causes because of the difficulty of diagnosis of illnesses that don't have a single biological pathogen. In addition some doctors may simply want to avoid labelling the patient with a diagnosis which may be potentially harmful (Lehman et al., 2002). However, these approaches can be misinterpreted by patients as assumptions of malingering and can result in feelings of shame and isolation (Saltzstein, Wyshak, Hubbuch, & Perry, 1998; Ware & Kleinman, 1992).

Consequences of Pain

Chronic illness affects more than just the individual sufferer. Illness disrupts family, job, and social functioning and can lead to excessive health concerns, depression and withdrawal from social activities (Miller, 1993). Research has found that people living with chronic illness have more negative feelings about themselves, lower self- esteem, less self-confidence and a sense of unhappiness and alienation (Gaston – Johansson et al., 1990; Miller, 1993). For chronic illness sufferers with physical symptoms that are not externally visible negative emotions may be exacerbated by the experience of being misunderstood by family, friends and health care providers. Furthermore these people often lose support from significant others even though social support is essential for reducing the stressful experiences of pain and illness (Gaston – Johansson et al., 1990). Miller (1993) noted that the effects of CFS extend far beyond the patient to the family and other social systems. Several studies have described how living with a chronic invisible illness results in a multiplicity of stressful consequences and considerable impact on daily life (for example Burckhardt, Archenholtz, Mannerkorpi, & Bjelle, 1993; Henriksson, 1994, 1995a, 1995b; Schaefer, 1997).

The Illness Experience

Having a chronic illness means living with a variety of changes and consequences in everyday life (Charmaz, 1983; Corbin & Strauss, 1987; Morse, 1997). Illness is one of the events that can jeopardise human dignity (Lanara, 1981). The word dignity is derived from the Latin words *dignitus* and *dignus*, meaning equivalence and credibility (Soderberg, Lundman, & Norberg, 1999). Credibility means that as a sick person and as a human being one's experiences are regarded as being true and that one is taken seriously. Often those suffering from CFS are not taken seriously and are regarded as being 'lazy' or 'malingering' and told their illness is 'all in their head'. Such reactions are threatening to the individual's credibility and hence their dignity, often at a time of significant physical pain and malaise. The concept of legitimisation indicates that – as perceived by the patient –the doctor formally acknowledges the patient's experience and treats the illness seriously (Ware & Kleinman, 1992). Patients whose doctors fail to legitimise their illness experience significantly more psychological distress than other illness sufferers (Lehman et al., 2002). Given that approximately half of CFS patients experience depressive and anxiety disorders (Deale & Wessely, 2000; Lee et al., 2000; Taerk, Toner, Garfinkel, & Ozersky, 1987) and the fact that scepticism from the medical profession results in psychological distress it becomes apparent that counselling may be an appropriate intervention for CFS clients who are experiencing the negative effects of the illness.

Psychologists can be of assistance to people with CFS in helping them to deal with the losses that accompany the syndrome (for example loss of ability, career, independence) and with the stresses of Chronic Fatigue Syndrome. At the same time; provision of the opportunity to discuss the illness in an environment of respect and dignity can provide essential social support. Anderson and Ferrans (1997) found that CFS resulted in "profound and multiple losses in jobs, relationships, financial security, future plans, daily routine, hobbies, stamina and spontaneity."

Biographical Disruption

Biographical disruption is a concept which describes how the structures in daily life become disjointed (Bury, 1982). Activities which were once completed as part of everyday life may now be extremely difficult or impossible and there may be a disruption between the individual's definition of themselves with regard to the past, present and future. Therefore, biographical disruptions bring to the fore issues relating to identity (Tuck & Wallace, 2000). It may require significant psychological work to sort through the losses of identity and aspects of identity which have shifted as a result of the illness (Corbin & Strauss, 1987; 1988). Psychologists can be of assistance to clients who need to do the psychological work of addressing these issues. This study aimed to explore how CFS could encompass a biographical disruption in an individual's life; what the implications would be for their identity in regard to employment and social life and how CFS patients come to terms with their new identity.

Literature regarding the disruption caused by CFS to an individual's life is scarce. Some studies have briefly

explored how CFS sufferers face disruption in the area of social functioning (Scheitzer et al., 1995; Anderson et al., 1997; Tuck & Human, 1998). Ware (1999) has examined the social consequences of the illness and the coping strategies developed to deal with them. The primary focus of this body of research is on the losses CFS patients experience as a consequence of the syndrome rather than on the significance of the illness for the individual's identity and life course (Tuck & Wallace, 2000). Current literature emphasises the need to examine the consequence of illness on the sufferer's identity and the need for caregivers, family and friends to understand the changes the individual is experiencing (Tuck & Wallace, 2000). Understanding is particularly important considering that CFS is, in a sense, a contested illness and some medical professionals and members of the public question its validity.

By exploring the possible areas of difficulty in the lives of those who live with a chronic invisible illness, it becomes apparent that there exists a potential for psychologists to be of assistance to CFS sufferers. This study aimed to determine the responsiveness of CFS sufferers to counselling and to explore what individuals wanted psychological professionals to know about their experience of the syndrome. Grant (2002) reports that it is amazingly rare for chronic illness patients to be directly asked how satisfied they are with their treatment. This study provided participants the opportunity to make available information that could inform counselling practice. It was hoped that this research might identify themes that are common to the experience of living with invisible chronic illness.

Maladaptive Coping

Maladaptive coping can negatively affect both physical and emotional health. Research indicates that people who cope with life events in maladaptive ways are more likely to become ill and to seek care in the year following the event (Spitken & Jacobs, 1971). A study examining patients with diabetes, cancer, hypertension, and rheumatoid arthritis found that measures of positive and negative affect were unrelated to the diagnosis but rather to the patient's perceived availability of coping resources (Felton et al., 1984). Psychological distress is experienced when what is at stake is significant and coping resources are perceived to be less than adequate for managing the demands of the situation. The greater the gap between the individual's perception of the coping resources available and the level required the greater the level of distress (Folkman, 1982).

There is general agreement in the literature that individuals with high levels of support are more likely to have better mental and physical adjustment (House et al., 1988). It remains unclear as to exactly how social support protects against ill health. Two main hypotheses in the literature are: 1) the main effect hypothesis; and, 2) the buffering or indirect hypothesis. According to the main effect hypothesis people with strong social support have better health than those with weaker support regardless of exposure to stressors (Broadhead et al., 1993). The buffering hypothesis suggests that people with strong support have better health than those with weak support only under exposure to stressors (Dalgard et al., 1995).

The stress buffering model is explained by Cohen and McKay (1984) in terms of social support being an essential part of the coping process. In the appraisal stage the coping requirements of the situation are assessed followed by the specification of interpersonal relationships to fulfill those requirements. Different types of symptoms will elicit coping requirements of different types of support (Cohen & McKay, 1984). Support includes tangible or material support, appraisal support, self – esteem support and belonging support. Only relationships that provide this support will operate as effective buffers. This point is extremely important in further supporting the role of the counselling relationship in the management of CFS. It is perceived support rather than actual support received that is the primary predictor of adaptation to illness (Kessler & McLeod, 1985; Wethington & Kessler, 1986). Shaw's (1999) framework is useful from an educative perspective in that it can be used to identify the level of information required by different types of people. For example those who prefer active, information–seeking coping strategies are more likely to require detailed information than those who prefer an avoidant approach (Miller, 1987). By identifying the coping strategies used by the client the therapist can tailor the educative aspects of the counselling process to the individual client.

Treatments

Treatments for CFS include drug therapy, exercise therapy and cognitive-behavioural therapy (CBT) amongst others. In response to the symptoms of CFS many doctors recommend counselling (McGrath et al., 2000). Counselling in primary care has been defined and applied in a variety of ways. For the purposes of this research counselling is defined as a non-directive, client-centred model which offers clients the opportunity to talk

through their difficulties and concerns in a non-judgmental and supportive environment. The aims of this intervention are to help clients better understand themselves, suggest alternative understandings, uncover the links between past experiences and current distress and to provide an environment for healing and growth (Ridsdale et al., 2001). Generic counselling has been shown to be as effective in the treatment of CFS as Cognitive Behaviour Therapy (Ridsdale et al., 2000). Furthermore, whilst there is no clear difference in the cost –effectiveness of counselling and primary care, that is a GP consultation (Harvey et al., 1998), counselling may be a useful adjunct at a lower unit cost which has demonstrated comparable effectiveness (Chisholm et al., 2001). Given that counselling has shown some evidence of being effective in the treatment of CFS, the fact that it does not have the serious side effects that often accompany drug therapies, and that many doctors are reluctant to treat CFS patients seriously, it is apparent that the counselling profession can be an important resource to this particular population.

Methodology

Research Questions

The main objective of this research was to explore and identify the main experiences of CFS for the individual sufferer. The research aimed to explicate the major experiences and events core to the experience of CFS in order to enable psychologists and counsellors to more richly understand the illness effects.

This study further attempted to identify the coping strategies of individuals with CFS and whether they are open and responsive to counselling as an additional treatment for their syndrome. Related to this was the examination of what types of support participants have received over the course of their illness and what CFS clients thought counsellors needed to know about CFS in order to provide effective psychological services.

Sample Characteristics

A total of 17 respondents participated in this research, six of which were internet based interviews. Of the sample four were male and 13 were female. The sample therefore reflected the gender composition of the wider CFS population. The mean age of respondents was 34.8 years with ages ranging between 19 and 56 years. Twenty nine percent of the participants were employed on either a part-time or full-time basis. It was difficult to ascertain how long the participants had been living with CFS because in the majority (15 out of 17) of cases their syndrome went undiagnosed for many years (ranging from two to ten years). Based on their own estimations it was revealed that the average amount of years living with the syndrome was 6.3 years with a range of one to 15 years. Of the total sample three had received counselling and none of the sample was currently in therapy.

Design and Procedure

The design of the present study was a one-off cross-sectional interview. Respondents had not been involved in any other research studies at the time and this study was the first in which they had been asked about issues pertaining to the psychosocial aspects of their experience with CFS. The study was based on participants' retrospective description. Participants were recruited through community advertising. A brochure outlining the research was displayed in libraries, universities, and shopping centres. An internet recruitment drive was also undertaken which involved joining virtual support groups and promoting the research rationale and importance of participation. This method was perhaps the most successful given that many CFS sufferers are unable to access libraries and shopping centres. Based on the responses it seems that internet access and support is very important to CFS sufferers as they are often housebound. Respondents participated in a semi-structured interview which was audio-taped and transcribed verbatim. Internet interviews were saved as text documents and all interviews were thematically analysed and had the themes authenticated by returning the results to respondents. Follow-up telephone calls or interviews gave respondents the opportunity to change the researcher's conclusions and to ensure the data reflected their experience. The interviews were place at the participant's home, over the telephone, via the internet and on campus. The length of the interviews varied from 35 minutes to two hours.

Ethical Considerations

A central consideration in this study was assuring confidentiality. Participants were advised that all responses were confidential, that all data would be de-identified. A second consideration was that many of the participants were unwell and hence were unable to be interviewed for long periods of time. In these cases, the participants were assured that if they wanted to stop the interview at any stage they were in control and could resume later or withdraw their participation entirely.

Data Analysis

The data provided by respondents was read by the researcher at least twice before analysis commenced to ensure that the researcher was immersed in the experience of CFS as explained by the participant. Following the initial readings the data was closely examined for emerging themes. Themes were compared and contrasted across other interviews for repetitive and comparative discursive analysis. The four major themes and sub-themes were returned to respondents for their comment, correction and validation.

Results

The respondent's rich descriptions of the CFS experience emerged under four primary categories: The Impact of Diagnosis, The Impact on Identity, Dealing with Scepticism and Social Support. A possible role for psychologists in a multi-disciplinary response to CFS was explored through this research. In relation to the findings related to usefulness of counselling sufferers identified that specialised knowledge should be required of psychologists working in this area.

The Impact of Diagnosis

The actual diagnosis of the syndrome emerged as an important component of the CFS experience. Prior to diagnosis the physical symptoms sufferers were experiencing were suggestive of serious and possibly fatal illness. In most cases participants had a lengthy wait between experiencing symptoms and receiving diagnosis – from 2 to 10 years. Diagnosis at least removed the possibility of terminal illness and gave an explanation for the physical symptoms.

Pre diagnosis

Fear Prior to receiving the diagnosis of CFS, most participants reported feeling frightened about whether or not the illness was fatal. As the symptoms of CFS waxed and waned new symptoms aroused fresh anxiety for CFS patients. The symptoms themselves were very incapacitating and implied an illness of a serious nature.

"You can imagine what we thought it was, I was hallucinating and dizzy and falling down."

Added to this uncertainty were the emotions raised by the medical diagnostic tests for diseases ranging from Alzheimer's to HIV/AIDS. CFS is diagnosed only after a range of other illnesses have been ruled out and patients are typically subjected to a battery of tests. The period of testing and waiting for results was described as extremely frightening for participants.

During the pre-diagnosis period participants also experienced anxiety about the mismatch between their experience and the reactions of medical professionals.

"They kept looking at psychiatric type, psychological type causes and asking me if I was depressed, [if] I had been depressed. I knew this was very different…"

Participants continued to experience strong physical symptoms and were anxious that doctors focusing on psychogenic etiology could result in missing a dangerous illness and wasting valuable treatment time.

Despair The study found that many people felt despair prior to their diagnosis and it was during this time that suicide was contemplated. A surprising number of participants (3 out of 17) had considered suicide as a result of their symptoms. The mysterious and irregular nature of CFS was, for some participants, overwhelming. The symptoms combined with the uncertainty caused some CFS patients to give up hope, *"It was a dark time, I cried myself to sleep. Yes, I thought about killing myself a lot"*.

Interestingly, it emerged that diagnosis helped to lessen despair and suicidal tendencies, *"If only you [psychologists] can catch us before diagnosis that's when people kill themselves."* A clear naming of the experience meant that the physical symptoms lost some of their mystery and menace. Patients were clear that the diagnosis lessened the hopelessness that accompanies an undiagnosed illness experience. *"We don't kill ourselves after the diagnosis"*. Poignantly, one participant observed that *"people don't die of CFS they die because of it."* This was an interesting distinction suggesting that while CFS is not a terminal illness the consequences of the experience of CFS may prove fatal.

Post-Diagnosis

Relief Receiving a diagnosis provided patients with the relief of knowing the illness was not terminal, *"I knew then that it wasn't anything sinister. It was a huge relief."* Knowing that they could now identify the illness their symptoms were linked to enabled participants to communicate to others what they were experiencing. *"I felt…I can now tell people I have a disease and its name."*

Having a vocabulary with which to explain why they were unwell was described as enormously important for participants. They described the diagnosis as relieving them of some of the self-doubt and cognitions of self-blame that often accompany CFS.

Having a term for the illness experience was also important in the sense that it allowed the illness to be externalised and dealt with as something tangible rather than as a personality flaw. Having a name for the condition made it more tangible and therefore more manageable. *"I felt at last somebody had finally put a name to this monster that was beginning to rule my life"*.

In general it appears that receiving a diagnosis is a positive experience for CFS sufferers. It provides them with some certainty and provides relief from long periods of wondering about the etiology of painful physical symptoms. Confirmation that the illness was not fatal was described as a huge relief that enabled individuals to explain the illness to their family and friends and to contact others with the same condition. Being able to provide information about their syndrome to others was described as extremely important by the participants. Some carried information sheets with them to give to anyone who challenged them about their illness when they were out of the home and 'supposed to be so sick.' Information explaining that physical symptoms vary over time was particularly helpful. Giving information letters to significant others outlining the syndrome was also reported as a helpful strategy in helping respondents re-establish understanding and social support.

The Impact on Identity

The impact on identity emerged as a major part of the CFS experience. Many responses clustered around the belief that participants' self-identity had been lost or replaced as a result of the syndrome and limitations illness imposed on the participant's activities and daily life. Some respondents reported that CFS had in fact improved their self-identity or changed their life for the better as they had learned valuable lessons about themselves and their coping abilities.

Sense of loss Lost identity emerged as a fundamental component of the CFS experience. Many participants indicated that as a result of CFS their lives had taken a turn for the worse.

"CFS completely changed my life, completely RUINED my life. It threw me into a painful, lonely, dark, very frightening place which I had to fight my way out of."

Associated with this loss was the grieving process which often follows a life changing experience.

"CFS is a daily battle to hold on to life. I have completely lost my old life; I have had to rebuild myself all over again. It's scary, and it hurts."

The physical limitations imposed by chronic fatigue illness mean that participants are not able to do the things they used to do, or have the same levels of enthusiasm and vitality.

"I was a high achiever, a real lover of life. I was an extrovert's extrovert. That has sorely changed."

It is interesting that this participant used the word *'sorely'* instead of *'surely'*. This could suggest that pain was a salient part of this person's experience with CFS. Negative changes in the self identity were experienced as a loss and considered to be exceptionally distressing. *"It turns you into a compromised person, I find it devastating."*

Furthermore, participants reported being preoccupied with thoughts of their old life and old self, *"I know I shouldn't dwell thinking where's my life gone and will it ever be back again?"* Friends and family of CFS participants also had to realise that they were changed people and were reported as experiencing a sense of loss as well.

"Friends that were my friends understood that I was going through a pretty big life changing experience. My other friends didn't realise and still wanted me to be the same person I was before."

Friends' reactions to the participant's changed identity were often reported as being negative and in addition to the sense of loss experienced within themselves participants often reported further grief over losing friendships.

"I became sensitive because I felt left out because my friends weren't asking me out and because I wasn't going out with them they weren't bothering to ring, they didn't understand. I felt ostracised".

Internalised Blame Attributions

Within the theme of changed identity was the impact of the cognition that the participant was in some way to blame for their illness. The external judgments of scepticism and disbelief from others created self-doubt for some sufferers who felt that if they motivate themselves more they would be able to beat CFS. "I blame myself, I don't understand why I couldn't push myself anymore…" Conversely, others internalised blame for the illness by attributing their poor health to their personal attempts to control the illness symptoms, "I blamed myself. Maybe I pushed too hard." These two poles of internalised blame create a no-win situation for CFS sufferers.

Externalised Illness Attributions

Some participants revealed that although they struggled with guilt and self blame they realised that ultimately they were not to blame for their illness, *"You wonder why you have it but I know that I haven't really done anything wrong and I don't deserve this"*.

"You wonder why you have done all these things for God and you say where is God? Why isn't he healing me? But you've got to believe in the journey and that's what faith is."

It seemed that when participants were able to recognise that CFS was not something that they had *"brought on themselves"* and that they were not to blame for having the condition that they coped better and had an improved sense of self.

Restructuring of Self Identity

For some participants their experience with CFS, while devastating, was ultimately considered to be positive in that CFS made them reassess their lives and appreciate what they had.

"It's the best thing that's ever happened in a weird sort of a way. You learn to appreciate life and what you have instead of what you don't have."

Because CFS affects every aspect of life some respondents reported an increased appreciation of small things.

"You learn to appreciate life in a completely different way to what anyone else can understand unless you've had this or some sort of life changing experience."

In addition, the experience of fearing a terminal illness and then receiving a non-terminal diagnosis was reported as an awakening for some participants.

"You learn a pretty big lesson, you realise that fine I shouldn't feel sorry for myself. I should feel blessed that yeah I did get a pretty bad illness but it can't kill me."

Furthermore, the illness afforded some participants time to reflect and come to a better understanding of who they were and what they wanted out of life.

"On the other side of the coin is the positive way this disease has changed my life. Being bedridden and unable to do almost anything I have learned to focus on other things, the spiritual and emotional side of life."

Time to reflect enabled participants to find where their priorities lay and prompted some life changing decisions such as to divorce, change careers or reassess the direction one's life had being taken.

"I went through an awful lot, I had a shocking time. It gave me strength though and after that time I went to university."

The Impact of Scepticism and Doubt

In all cases, experiencing the scepticism and judgments of others was reported to be one of the most powerful and painful parts of CFS experience.

Dismissive Medical Professionals In almost all cases, participants reported frustration in their encounters with medical professionals who invalidated their concerns and dismissed their symptoms. Frequently, CFS sufferers reported being accused by the medical profession of being malingering hypochondriacs.

"I would tell the doctor 'I'm so tired and I can't do anything what's wrong with me?' and the doctor would say 'get over it, you'll be right'."

Respondents felt that their repeated and desperate attempts to convince health professionals that they were experiencing real symptoms were often met with irritation, *"I think the doctor thought 'God this woman is an idiot'"*.

Direct accusations were not necessary for patients to sense they were not believed. Respondents often inferred from the Doctor's blasé response that the Doctor thought

they were malingering. Some responses raise concern about professionalism. One participant reported being told by her GP to take a protein milkshake and when she returned after a week of no improvement being laughed at and told; *"Oh silly, you don't expect the milkshake to work so quickly do you?"*

For women there was the added complication of having Doctors dismiss their fatigue as being a normal part of the pressures on modern women. A medical professional reportedly told one CFS sufferer, *"It's hardly surprising you are tired you have three kids and you work full-time"*. More offensively some female respondents were reportedly told that their symptoms and their fatigue was related to menstruation or *"being hysterical."*

Scepticism The majority of participants relayed how significant people in their lives did not believe what they were experiencing was physical and thought that they were simply suffering from psychological distress.

"The pain of having family, doctors, teachers and friends look at you and say 'it's all in your head' is almost as bad as the physical pain that we struggle with daily."

Furthermore, CFS sufferers reported often being told that they were sick because they were lazy malingerers who were trying to get out of work or school.

"I have experienced a huge amount of prejudice and disbelief. I've had more than my share of comments like 'Oh, I must have that, I'm ALWAYS tired', 'there's no such thing as CFS', 'you're making it up', 'Its all in your head'. These do nothing but make me feel ashamed to have such an 'invisible' illness."

Scepticism was something which every participant in the study reported experiencing in some form or other.

A minority of respondents (three) reported that significant people in their lives (family, friends, partner and work colleagues) accepted their illness and associated limitations. However, this acceptance normally came after years of living with the symptoms and eventually receiving a diagnosis. Having a name for the illness was described as important in the sense that it allowed others to learn about CFS and therefore to accept their experience as being real. Only two participants revealed that they were believed by their family from the onset and both had other family members who had previously suffered with CFS. "They believed me because Mum had it."

Coping with the disbelief from others was particularly distressing when the individual relied on these people for practical support.

"Always relying on another, not being independent is hard to accept even after so many years. It actually gets harder as the years go past."

As a consequence of CFS sufferers are often unable to do many things that are necessary for everyday life, such as driving, cooking, and cleaning. Consequently help is needed to get to medical appointments, to shop, pay bills and maintain the home. Relying on people who don't believe CFS is an illness was reported as particularly damaging during a time of vulnerability and dependence.

The Impact of Self Doubt and Questioning

Some CFS sufferers reported that, as a result of experiencing ongoing scepticism from others, they started to doubt their own physical experience.

"I started thinking, 'I am imagining this', because people treat you like you are imagining this."

One participant revealed quite poignantly, the pervasive social scepticism about CFS, in her description of her understanding of the illness prior to her own experience.

"I had read about CFS and thought 'what a yuppie sort of disease that is. What a waste of time people are that say they have CFS, I just think it's a bit of a wank'. But I was wrong."

The constant judgments and criticisms of others was described as eating away at the coping resources of CFS sufferers.

"It takes effort not to listen to that voice that whispers 'maybe they're right, maybe if you just tried to get out more, tried to do this, tried to do that it wouldn't be so bad.' That voice is there even though I KNOW how real this disease is and how much devastation it causes. That voice is a result of 14 years of doctors, friends, teachers and various other people telling me that 'there's nothing wrong with you.'"

The Impact of Scepticism and Hostility

It was reported by participants that the disbelief and hostility they received from others was a devastating component of their experience of CFS. In one case this disbelief translated into work-place harassment where a

participant was badly bullied by a colleague at work who took it on himself to convince her that her illness wasn't real. Respondents reported that others seem justified in taking an aggressive stance about CFS and that it was tiring and frustrating not to be able to defend oneself.

"I did fight back but it was so continual. I needed my energy for me, just to get out of bed everyday, just to exist."

Others reported that the scepticism from the doctors as particularly damaging because they expected understanding and support from the medical profession.

"I would come home and realise how insulting the doctor had been to me and I was furious with myself for not having a comeback. I just didn't have it in me to say anything at the time."

Many people reported being told aggressively by others that their CFS was 'faked' and just an attempt from them to escape responsibilities and commitments. Participants responded to this with a sense of amazement and reported that they would far prefer unpleasant responsibilities to their symptoms.

"I ask you who would want to fake this, who would want to live with this monster?"

Others were extremely offended by suggestions that they were faking CFS.

"I am not some person lounging around on the dole trying to screw the government for money. I am educated, responsible. I am studying. I mean get real."

Social Support

The illness of sufferers was only initially believed if another family member had previously experienced CFS. Wider scepticism and hostility towards CFS limited the ability of sufferers to access social support. The theme of support is therefore closely related to that of scepticism. When participants were believed they were more likely to receive support, at least in the initial stages of their illness. From the results of this study it seems that there is little social support for people suffering with CFS. In some cases family and friends were initially supportive and gave physical assistance but this support waned as the illness persisted.

"At first people feel sorry for a sick friend, but when the illness drags on for weeks, months and years they forget and simply move on. I was left behind."

Lack of Tangible Social Support Participants reported that support was minimal and in some cases non-existent. It appears that the major reason that sufferers do not receive adequate help and understanding from others is due to the invisibility of the illness' symptoms and its low social validation.

"Had I had cancer, or MS (multiple sclerosis) or another well known and accepted chronic illness people would immediately understand."

For some participants, CFS led to outright hostility from family members. One participant stated shockingly, *"My brother says it would be the best thing all round if I was dead."* Other responses were reported as compounding the feelings of loss and despair that accompany the illness.

"My family cut me off….. That killed because I needed support".

"My sister pretended I was not alive more or less. Never came up to the bedroom to say 'Hi' or visited me in the hospitals."

Lack of Emotional Social Support When family members refused to acknowledge the illness their unrealistic expectations of the CFS sufferer were reported as an additional burden. *"They don't believe I am sick so they have all these expectations of me that I can't fulfill."*

Participants revealed that some people blatantly accused them of laziness:

"Others have indicated that they don't believe in the disease and make comments such as 'Oh I know people with CFS, they're that lazy!' – this shows their ignorance as to the severity of the disease."

Often the consequence of lacking support is that the sufferer retreats and learns not to rely on others, becoming even more isolated.

"Because of it all I have withdrawn, I just keep my distance from people. They don't understand".

This can create a cycle of decreasing social engagement and subsequent reduction of social support avenues for CFS sufferers.

Coping Respondents reported that increased support from friends, family, other sufferers and the medical profession resulted in better coping with CFS. Talking to others with the syndrome was cited as particularly useful. Maladaptive coping occurred when participants did not have a diagnosis, had little social support and/or were the target of much scepticism. Examples of maladaptive coping were reported as thoughts and fantasies about suicide, over-eating, social withdrawal, low self-esteem, internal illness attributions and self-imposed isolation. Healthier coping resulted when participants felt acknowledged and supported. Examples of adaptive coping included commencing study, offering advice and support to fellow sufferers, external illness attributions and learning from and reflecting on the experience of CFS. These findings indicate that social support is critical for preventing maladaptive coping.

The Role of Counselling

Counselling emerged as an area that sufferers felt needed to approached with sensitivity. A primary obstacle to effective therapeutic intervention was that many CFS sufferers interpreted offers of counselling as implying that their illness emanated from psychological or emotional disturbances. In addition, participants indicated a lack of understanding as to what counselling is and what psychological services might incorporate.

Confusion about Counselling This study found that many CFS sufferers often had stereotypes and misconceptions as to the role of psychological services. As a result only one in five respondents had received counselling and none were currently engaged with psychological services. One participant thought that psychologists meant a Freudian approach that would delve into private issues of birth and sexuality.

"Question you about your sex life, your childhood, accidents at birth. They will go down every path know to psychologists, they are all going to be barking up the wrong gum tree anyway."

A core reported fear was that a psychologist or counsellor would try to get to the psychological "root" of their CFS, thus colluding with predominant of social scepticism regarding CFS.

"I think it is a wonderful idea although many CFS people even to this day fear counselling as they have been told countless times not just by everyday people but by the medical profession who we all want to trust with our health….that it is mental or it is in our heads."

Possible Role for Counselling Services The majority of participants (15 out of 18 participants), after receiving the definition of counselling taken in this study were positive about a possible role for psychological services for CFS sufferers. Specifically, respondents felt that having someone to listen would be a valuable service.

"For a CF person to be listened to and understood is a rare experience for them. That pretty well sums it up".

The main responses were that participants thought counselling would help them the most in adjusting to their new life and the new limitations imposed by the illness. Once respondents understood that counselling was not implying an emotional cause for CFS they considered it could be useful in helping people adjust to the multiple effects of the syndrome on the person as a whole.

"We are bodies, minds and spirits and your emotional life is going to impact on your body. Anything you can learn about yourself will help…"

Participants reported that they often received unwanted advice from well meaning friends and relatives who considered the "cure" to be simple and based on one's own motivation to get better. Counselling could offer a non-judgmental, non-directive alternative to the "pseudo-counselling' offered by friends and family.

"It would be therapeutic just to have someone to listen, for my own sanity, someone who will just listen and not offer advice".

Respondents also thought that counselling would be helpful in terms of educating and supporting family members who live with and care for CFS sufferers. Participants suggested that it was important to advertise psychological services and to particularly clarify the role of the counsellor as a supportive, non-judgmental non-directive role.

"I'll tell you what I think is important. I think it's important to get counselling. I think there should be more psychologists and I think it should be more publicised that people are willing to listen".

Past Experiences with Counselling Some participants (3 out of 17 participants) had received counselling in the past. It emerged that all had had negative experiences with psychologists who did not believe them and as a result they were hesitant to seek further psychological services.

"I have been to counsellors who clearly didn't believe in CFS and were patronising and rude. It took me a long time to get over this and it's not something I'm ever likely to forget."

However, even participants who reported negative experiences did go on to eventually find a therapist they were comfortable with. No participant gave up completely on the notion of professional psychological support. Each recognised that the dissatisfaction lay with the individual therapist not with counselling *per se*. The therapeutic relationship was described as particularly useful in validating the client's illness experience. Those who had had positive experiences cited the key to the success of the therapy as having someone in whom to confide and having the therapist believe the client's physical experience. Such psychological support helped the patient to feel stronger in themselves and to block their own self doubt.

"You realise counsellors are aware of these things and you are not mad after all."

Specialised Knowledge Required for Effective Psychological Services

Overwhelmingly participants indicated that psychologists must have a deep and thorough understanding of CFS and must understand the debilitating physical symptoms. Engaging the CFS client with respect and compassion was also reported as crucial.

"Above all compassion and understanding. People with CFS not only have to deal with the physical symptoms and limitations that the disease brings, but the emotional strain also."

Involvement with CFS research and awareness of the latest developments was considered to be very important.

"Personally for me and a few of my CFS friends it helped us when we knew that the counsellor was not just counselling but was indeed involving himself in the CFS Community."

Respondents felt that psychologists should be aware of their own attitudes towards invisible illnesses, before commencing treatment with CFS sufferers. Participants indicated that they were very sensitive to scepticism and astute at determining the counsellor's attitude: *"Even if someone is saying they believe you, it's not hard to tell whether they REALLY believe you"*.

Consequently, therapists must be totally committed to understanding the world of the CFS client, even if they harbour some scepticism of the condition, and be aware of how their scepticism could affect their relationship with the client. This is not to deny that some people malinger or may psychosomatise problems. Rather, this study emphasises that psychologists need to be fully aware of what CFS is and its presenting symptoms in order to be able to identify and support those with CFS illness.

Practical Aspects of Psychological Services This research revealed that CFS clients also have practical requirements for successful therapeutic process. It emerged that participants did not always want to travel to the counselling session but did not want the counsellor to come to their house either.

"I am too weak for any of that….I can't hold a conversation some days".

Telephone counselling was mentioned repeatedly as an attractive alternative because it enabled CFS people to control when the session took place and the length of time spent talking to the psychologist. It also meant that CFS clients did not feel guilty for not attending a session when they were unwell. Physically, for some, attending counselling was not possible even if it was over the phone.

"My energy is at a very fundamental level of survival. I crawl to the toilet. I can't go to counselling."

This study revealed that CFS clients really value a counsellor who is willing to be flexible and adapt to their limitations.

"I certainly like what my counsellor did; he arranged a time schedule as he knew a 45 minute session would be too much. Also made it clear that at any time I could tell him I needed to stop the session."

"He was wonderful!!! We only did 15 minutes approximately. Which gradually over two years went up to 30 minutes."

The findings of this study suggest that psychologists need to consider alternative and creative ways of delivering psychological services to chronically ill house-bound clients.

Meta-theme A meta-theme that emerged from this study was that many sufferers anthropomorphised CFS as a calculating monster controlling them and their lives. Sufferers described CFS as a 'being' that drains them of their energy, embezzles their identity, discredits their experiences, tests their relationships, threatens their dignity and promotes self- doubt. CFS has implications for almost every aspect of the sufferer's life ranging from how they feel about themselves (identity) to what support they receive from others and to how others perceive them (scepticism). The experience of CFS is all encompassing for sufferers and whilst some positive aspects were reported from the experience of having this illness, it appears that CFS is an enormously distressing, frightening and painful illness. The overwhelming impression given by the participants was that if they could 'get over' CFS then their quality of life would greatly improve. From the perspective that CFS controls their lives and determines their emotional and psychological health many sufferers described CFS as an entity which had power and control over them. CFS clearly has a major impact as an illness, and has a pervasive effect and impact on the sufferer's life.

Discussion

This study aimed to delve into the experience of CFS and explore the many consequences this illness has on the lives of people who suffer from it. Whilst gaining a richer understanding of the tapestry of CFS it was hoped that a justification could be made for the role of psychological services in the treatment of this population group. Furthermore, this study attempted to question what potential clients wanted from a psychologist and what they wanted the therapist to know about their experience. In some ways this aspect of the study endorses the new directions being taken by the health-care industry to a service industry responding to consumer demands and satisfaction.

Modern medical systems are being redesigned to recognise the contribution of a range of professionals who work together to manage 'total patient care' within cost constraints. DeJong and Jackson (1999) describe the changes as a transformation of our compartmentalised and insular health system, which is fuelled by organisational and professional tribalism, into one that regards itself as a single entity which serves the patient/client. The broader context of more acceptance of complementary treatments for medical problems is providing a new avenue for psychological service provision.

The Impact of CFS

Despite the concerns of some medical professionals that diagnosing a patient with CFS could be unhelpful, this study revealed overwhelmingly that receiving a diagnosis was very positive for CFS sufferers. A diagnosis for some respondents represented a tangible confirmation of physical symptoms and helped allay some of the fear and mystery behind their illness. Unfortunately due to practical limitations this study did not investigate individuals who displayed the symptoms of CFS but had not yet received a diagnosis. Understandably this would be extremely difficult to accomplish.

Two considerations for the implications of a diagnosis to psychological services must be made. Firstly, despite the difficulty in obtaining access to an undiagnosed group counselling would still be extremely useful in helping them to talk about their fears and concerns and the uncertainty that accompanies the gamut of tests that many undiagnosed patients face. Doctors and specialists could recommend counselling to their patients when commencing with diagnostic testing. It is understandable that doctors have limited capabilities and time in which to help with patient concerns and this is an area where psychologists and other counselling professionals can make a strong contribution. Future research should examine the willingness of patients and doctors to access counselling when people present with symptoms and are undergoing testing.

Lack of Support for Sufferers

This study indicated that lack of social support was a serious problem for people with CFS. Support was considered to be both practical and emotional and was closely tied to the theme of having symptoms believed. To have 'support' was defined by respondents as significant people knowing they were genuinely ill and responding to their illness needs.

Lack of support led to participants feeling isolated and as though they were a burden. Participants indicated that they would desperately have liked to have had someone to

talk to about their symptoms and the emotions related to having to adjust to new physical limitations. Psychological services would be appropriate at this juncture. Given that social support is often absent in the lives of CFS sufferers it is important to ensure that counselling professionals can be accessed and that professionals are aware of the value of positive mutual support groups for this population. In addition to providing one-to-one support counselling professionals should also facilitate the development of mutual support groups for CFS sufferers.

The Impact of the Scepticism of Others

Not being believed is a huge part of the CFS experience. As mentioned previously when an individual is not believed and their credibility is questioned their dignity is jeopardised. This study revealed that scepticism from others was pervasive and a painful part of the experience of those suffering with CFS. The consequences of scepticism and aggression from others had numerous negative consequences at a time of physical distress. GPs can be trained in the symptoms of, appropriate responses to, and role of psychological services for CFS sufferers. Counselling can be especially useful for clients who are starting to doubt themselves or who are angry about the constant scepticism they receive from others.

Identity

The theme of identity emerged as being significant in this research. Incorporated in this were the sub themes of lost identity, new identity and dislike/like of new identity. Participants indicated that an immense grieving process commenced when they got CFS because they no longer were the person they used to be and they had to adapt to their changed identity. In some situations changing body size due to reduced physical activity was also a major concern and led to a decline in self-esteem. Participants also revealed that sometimes they blamed themselves for their illness and thought that maybe they were responsible for what was happening to them. On the other hand this research also found that some participants considered the experience of CFS to be extremely positive resulting in self revelations and increased appreciation of life. In this instance counselling can help to cement this reframing of the experience so that when physical symptoms are severe these cognitions may be accessed.

Coping

This study revealed that when participants felt supported by their family, friends, and medical practitioners they were better able to cope with CFS. Lack of a diagnosis, minimal support and scepticism from others resulted in some participants coping maladaptively. Examples of maladaptive coping were suicidal thoughts, social withdrawal, depression, and low self-esteem. A coping strategy used by some participants was overeating. This is both an emotional – focused and a problem-focused strategy as it was believed that eating would strengthen and energise whilst at the same time it was comforting. Other participants coped with CFS by talking to others with the condition, a strategy which greatly enriched their lives and lessened the burden of the illness. Consistent with the literature (House et al., 1988), this study found that increased social support enabled better coping with the syndrome, providing further support the role of counselling in CFS management.

Counselling

This study demonstrated that it is important when counselling is marketed to an illness population that it conveys the intentions of the profession: to help with the adaptation and adjustments required by such an experience. Without this understanding it is easy for people already experiencing hostility to assume that psychologists might collude with the wider social scepticism to which this group is so averse. When it was explained during the study that psychological services could help in coping with the syndrome and its associated consequences, an attitude shift was observed. Participants indicated that they would be open to counselling only if it was focused on the ‘here and now’ and dealing with the emotions and consequences of CFS. This study indicated that many people associate counselling professionals with ideas of therapy as solely focused on one’s sex life or birthing experiences. Clearer description of psychological services can help to dispel common misconceptions that could prevent people from accessing counselling as part of their CFS management.

In terms of what participants wanted from a counsellor the major prerequisite was knowledge of the condition and a belief in its existence. In addition, all the usual requirements of a counsellor were expected; compassion, empathy, and presence. The implications are that psychologists need to be educated about invisible chronic illness and have some awareness of what it means for the sufferer. Every experience is different but having a general familiarity with what the condition entails is essential for professionals who wish to convey

appropriate understanding. In terms of the practical requirements of CFS clients, therapists must consider that hour-long sessions may be too strenuous and should endeavour to be more flexible in the delivery of counselling. Suggestions include telephone counselling and the use of the internet to convey information or support for house-bound clients. Furthermore, CFS clients in particular should not be kept waiting for sessions and therapists must be conscious of the fact that for some clients even getting to an appointment may be utterly exhausting. The implications of these findings for the profession are that student psychologists must receive adequate training in telephone counselling for such populations (Geldard & Geldard, 2001). Participants in this study indicated that this was a service they would like to access if it was available.

Limitations

The generalisability of this study's findings is limited by sample characteristics and size. The sample used in the study consisted of people at different stages of the illness experience. For some it was a recent adaptation but others had had CFS for many years. The retrospective nature of the study has an influence on how the experience is described in that time may distort memories of the illness experience and any counselling received. In addition, it is hoped that in recent times attitudes towards invisible illnesses are becoming more liberal than they might have been many years ago (a change that will impact upon the illness experience). The sample size of this group was small. According to Conrad (1987) at least 20 participants are required in order to obtain a sufficient breadth with regard to variations in illness experience. Accordingly, this study should ideally have had between 20 and 30 respondents. Future research may wish to increase the sample size in order to more comprehensively examine a variety of illness experiences.

Implications

There are three major implications of this research for psychological service provision. First, the CFS experience includes the effects of lack of social support, aggression and scepticism from others and identity concerns. Counselling can offer the support, validation and acceptance that can help with adjustment to CFS. Second, the nature of psychological services is not well understood in the CFS community. It would be of benefit for the profession to clarify and outline the ethos of the therapeutic process in order to encourage chronic illness sufferers to approach and embrace counselling. Third, the practical limitations of CFS sufferers mean that practitioners need to explore the possibility of delivering counselling in more flexible, creative ways rather just in the standard counselling tradition of hourly appointments. Psychologists may need specialised training telephone counselling and possibly in the use of internet access as a therapeutic tool. In addition, counsellor education must include a component on invisible chronic illnesses in order to ensure therapists are appropriately responsive to this population group should they present for therapy.

Conclusion

The experience of CFS can be summarised as being devastating, isolating and as having a profound impact on all aspects of a sufferer's life, particularly on their identity. CFS has the same debilitating effects of other illnesses but also results in social stigma and aggression which can lead to social isolation. CFS is not widely known as an illness and hence sufferers often do not receive social support through their illness experience. In the main CFS was described as debilitating experience which had far-reaching consequences for participants' lives, relationships, activities, employment prospects and sense of self. Overwhelmingly, the participants in this study indicated that social support is greatly lacking in the experience of CFS and that there is a critical need for supportive psychological services as part of a holistic treatment plan for CFS.

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Research Profile

Bailey Bosch has a particular interest in health and the role of mental well-being in safe-guarding against physical illness. Physical activity and the associated emotional and cognitive benefits are another area of interest for Bailey. She hopes to further explore the role of exercise in promoting self-esteem in vulnerable population groups, such as the elderly and teenage mothers. Bailey's previous research has included an examination of the role of professional allegiance in the medical accident reporting behaviour of health professionals and the State's response to road safety, specifically speeding, in Western Australia.

Katie Thomas is a psychologist who works as a clinician and researcher. Her clinical experience includes group and individual psychotherapy across a range of presenting issues, with particular clinical interest in postnatal depression and its impact on children. She lectures in Refugee and Migrant Health at the Centre for International Health and regularly conducts governance analysis and strategic community development. Her research interests include the impact of globalisation on social fabric and children's rights and wellbeing. Past research includes analysis of the use and abuse of power, female workloads, rural fragmentation and chronic illness attributions. She has a Clinical Diploma in Hypnosis and is a member of the Association for Counselling Psychologists (ACP), the West Australian Sexology Society (WASS) and the Society for Community Research and Action (SCRA).