HEALTH AND ILLNESS
A Socio-Cultural Perspective on Client Care

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Declaration

The work presented in this thesis has not
been submitted for a higher degree to any
other university or institution

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Abstract

This was a descriptive, grounded theory study designed to explore relationships between social and cultural phenomena in an individuals life and the resulting impact on health and healing. Ten subjects were involved in an audio-taped interview style forum.

The methodology utilised to form an underlying conceptual model was the cross comparative technique, where data was continually analysed and compared for re-occurring themes and variables. Themes were then clustered, and delimited, leaving the conceptual model exposed.

Illness was seen as a time of challenge, where the individual's self-image was threatened. Healing could be then seen as an adaptive process that allowed homeostasis to re-occur. There were several key social factors that allowed successful adaptation to occur; most noticeably, social support to re-affirm changes in self-image, and a trusting and empowering carer-client relationship that allowed for confidence in recovery.

The study discerned some implications to the practice of nursing care, where an holistic, open-minded, informative and communicative relationship with the client was found to be one that most benefited or promoted overall health achievement. In the study the complex and interactive nature of the individual and the forces acting apon him or her in illness was also illustrated.

Chapter 1
Introduction

Introduction

This study investigated the influences that social and cultural forces had on the nature of health and illness, with a particular focus on client care. This chapter sets out the background to the problem, provides the aim of the study and delineates the research question and purpose statement.

Background to Problem

Helman (1994, 107), defines illness as the:

> "Subjective response of an individual, and those around him, to being unwell; particularly how he, and they, interpret the origin and significance of this event; how it affects his behaviour, and his relationship with other people".

The schism between a holistic and a reductionistic definition of health has been long running and ever widening, and has been instrumental in the differing modalities of care we can see between the bio-medical and primary health care approach to individual client treatment.

In the current bio-medical health care climate, Cohen notes that it is becoming increasingly obvious that clients are being "encouraged into passivity and dependence" (Cohen, 1988, 8) rather than being supported in promoting health-benefiting behaviors. Thomas (1977, 43 – 44) supports this belief when stating that;

> "Nothing has changed so much in the health-care system over the past twenty-five years as the public's perception of it's own health. The change amounts to a loss of confidence in the human form. The general belief these days seems to be that the body is fundamentally flawed... always in need of support by health care professionals".

He further adds that we as a people if left to rely on a 'fix it' or curative attitude to health care instead of a preventative, will find ourselves "in some danger of becoming a nation of healthy hypochondriacs" (Thomas, 1977, 44).

This general trend towards ill health in the community can be seen already when noting, that although general life span is increasing and infant mortality rates are falling, more people are reporting ill health than ever before (Barsky (1988, 78).

Green partially explains this phenomena in her critique of current health care practices (1991, 164) to be the result of self-responsibility being taken from the individual. That a person's health status has increasingly become the domain of health care professionals, rather than the capacity of the individual.

In a health care world bent on increasingly more technological and less easily understood care, the client is fast becoming left behind in his or her own race for well-being, and dependence could again be seen as the end result. When viewing care as the empowerment of the human spirit and the finding of a homeostatic balance between mind, body and soul, such a dependence is unacceptable in the course of aiding individuals on the path to wellness.

In essence, the presumption of this project lies in the fact that human beings exists not necessarily as a sole entity, and that their social structures around them and cultural conventions serve to themselves as much as their height, weight and vital statistics. In

understanding the needs of the individual, the needs of the community will also be understood, and care should ultimately be aimed at using the powerful community assets of the individual in successful management of the client. The quality and successful maintenance of client relationships is as much determining to health as the diet that he eats. Pedersen (1996, 746) agrees when he sees that:

> "Disease needs to be set in an ecological framework that puts humans and the natural and social environment together as equally causal and productive of health or disease".

Aim

With this definition in mind, this research project is aimed at exploring the phenomena of illness and correspondingly health, in a continuous, unified and interactive paradigm. It's purpose is to develop a model of social and cultural forces that influence a persons' response to illness, and therefore try to improve client empowerment, independence and an ongoing move to further health sponsoring behaviors.

Purpose Statement

Study Question:	How do cultural and social values influence health status?
Study Aim:	To develop a model of social and cultural forces that influence a persons' response to illness.

Chapter 2
The Nature of Health and Illness

Introduction

In examining the many sources that have at one time presented interest, or researched the phenomena of illness it is important to delineate different fields of consideration. Primarily, one must define and contrast the various models of care. One must then look toward how each model views and treats the ill individual, and by what means. The act of care itself must be thoroughly examined, as also the relevance of social support and the efficacy of care. More importantly these factors placed within the uncertain social setting of illness, the individual fears and constraints of the client and the overall environment in general. With this in mind, this literature review aims to describe the nature of illness from a socio-cultural perspective, and to discuss relationships between illness and the wider social platform of a person's unique, subjective reality.

Comparing Different Modalities of Health and Care

In developing a model of health that views the individual in an everyday, cultural setting, it is necessary to contrast the principles of holism and reductionism and in the process review more specific modalities of care offered by past theorists.

Holism is a philosophy of perception where "individuals are (viewed as) greater than the sum of their parts. The individual is viewed in terms of interactions, relationships, and processes that combine to form a unique whole" (Kinnion & Kolcaba, 1992, 220). The individual is not simply perceived as a mechanistic or 'fractured' sum of traits, but a related, synthetic unity of acts (Cohen, 1998, 8). Health is therefore seen as a "dynamic process that takes into account all the decisions we make daily" (Edlin, Golanty &

Brown, 2000, 6), a "state of complete physical, mental and social well-being, not merely the absence of disease or infirmity" (WHO, 1988, 1).

Health is consequently divided into physical, psycho-social and spiritual vectors of wellness that all work in "subtle and indefinable ways" (Cohen, 1998, 9), together. Illness can be defined as any factor that impinges on the everyday management of these 'fields'. (Dossey, Keegan, Guzetta, & Kolkmeir 2000, 14-17), while the manifesting disease is believed to be the tip of an existential iceberg and the "means of communicating to the mind that something needs to be changed, removed or added to one's life" (Peterson, 1996, 30).

Martha Rogers describes a complex nursing theory based on a similar appreciation of the human being. Her theory attempts to describe life processes, and understand the individual nature of a human being within the fields of his or her own external and internal environment. (Rogers, cited by Barrett, 1990, 5). It is at once, both a developmental theory and a nursing care theory, amalgamating scientific and philanthropic principles of the human being. The core tenants being:

> "Humans are unified wholes, that are more than the sum of their parts.
> Humans are constantly interacting with their environment.
> All things in life are unique (no two things are the same).
> Humans develop patterns of behaving, and their behaviour becomes relatively predictable.
> Humans are distinctive in their capacity for abstract thought, imagery and emotion" (Rogers, 1983, 47).

In Rogers' theory, the 'whole person' is shown to have distinctive 'abstract' strengths that are related to the mind and/or emotive states. The carer then can target the client's ability to imagine or conceptualize, in the process of treatment, with the understanding that what affects the body, must effect the mind (Rogers, 1983, 19-21). Illness is seen to

be poor adaptation or poor development in the client and care is "directed toward the nature and direction of human development" (Taylor, Lilis & LeMone, 1993, 56).

Jean Watson presents a similar theory to Rogers, which is primarily based also on a holistic understanding of an individual. Illness is viewed as" a congruence between the self as perceived and the self as experienced" (Watson, 1988, 27). An individual is viewed as a unity or harmony between "the mind, body and soul" (Watson, 1988, 29), and care revolves around the principles of "kindness, concern, love of self and others and a respect for the spiritual dimensions of the person" (Watson, cited in Wesley, 1992, 112). Human beings are perceived as creatures capable of evolution in a thoughtful, emotional and spiritual sense, and in times of illness, care must be tailored to facilitate the client "developing a higher sense of self" (Watson, 1988, 43). Illness is therefore, not necessarily seen as only negatively impacting the individual, but also as a time of challenge, growth and adaptation (Wesley, 1992, 111). A time of remodeling and purposive change designed to promote growth of the individual. This model of care shows the non-polar aspect of health and illness in its most simplistic form, where health is seen in terms of evolution, or change and not just 'healthy' or 'ill'. The carer enters into a relationship with the client, which seeks to explore the client's adaptive strengths and weaknesses and guide the client towards a state more conducive to health and growth.

In a reductionist belief system we see inter-related subsystems of an individual's internal being, working with each other in a 'cog-like' fashion, where illness or disease is carefully isolated and removed (primarily by invasive therapies or pharmacological treatments). Disease is seen to be specific states, and wellness is the absence of such states. A person is 'healthy', when not suffering from any known abnormality; and a fundamental focus is placed upon the 'curing' of disease, rather than health promotion.

In a reductionist (bio-medical) model of care, treatment is most often sought if the state of the ill person has seriously impacted on his or her own reality, and specialists (which comprises yet a further reduction of the human being) are often the end point of care. The

bio-medical model is based upon a quantitative, scientific regime of causality and the offending effect. It therefore has difficulty in diagnosing or treating states or disorders that have a complex or multiple aetiologies (Kinnion & Kolcaba, 1992, 218-230).

Cohen (1998, 9) argues that modern day, reductionistic medical practices "encourages the passivity and dependence" of the individual suffering from an illness to the medical system treating him or her. Such a divide between the bio-medical and holistic ideals can also be seen in the works of Dorothy Johnson when she explains the difference between a bio-medical viewpoint (where medicine studies pathogenic changes in the ill person) and a behavioral understanding (whereby care is focused on changing client behaviors to practices that best advocates health) (Johnson, 1980, 54). Johnson advocated the importance of client 'self-care', where it was the health practitioner's role to facilitate the client's journey towards his/her own health, and that "care is directed toward caring for the whole client to facilitate effective and efficient behaviors necessary to prevent illness" (Taylor, Lillis, & LeMone, 1993, 52).

We see a shift of paradigm from traditional standards that searches for a more inclusive definition of health. A definition that gives weight and relevance to the client's social and behavioral context, and that seeks to understand health as a series of "adaptive responses to maintain balance and comfort." (Johnson, 1980, 53). The goal of the primary caregiver in this model is to let the client regain the homeostatic balance that he or she has lost in the course of her/his illness.

Madeline Leininger exposes yet a further stratum in the perception of the individual and consequently another style of care in her theory of trans-cultural care. Her conceptual model is based on the principle of care being a trans-cultural process (Leininger, 1988, 156), where treatment is uniquely modeled for the culture and situation of the client. Treatment involves attention being paid to three primary care functions; cultural care preservation, cultural care accommodation and cultural care repatterning. The culture of an individual is seen to be the blueprint of the individual's mode of thought, "a means to adaptive decision making and a door to subjective understanding" (Taylor, Lillis, &

LeMone, 1993, 52). The individual is seen therefore to be unique, but dependent on cultural law and social perception for crucial self-definition. Relationships with others are seen to be the vehicle of self-expression, that provides a backdrop of meaning and understanding to both the client and carer.

Carer-Client Relationship

When looking at the act of care more selectively, one of the primary vehicles of client management resides purely within the bond between the client and carer (Johns, 1991, 1092). Huss, Buckwalter & Stolley (1988, 31-36) and Ross (1990, 275), conclude in their research into client satisfaction of care that "forming (a) therapeutic relationship with the patient", is the cornerstone of true treatment.

Several care theorists and researchers have explored the nature and importance of the carer-patient relationship. King saw the relationship being an agreement between client and carer, where both "set goals, communicate and explore means" (King, 1981, 17). This framework of care sees the importance of the primary carer to help "create opportunities for the person to control the environment of care...to foster growth, learning and healing" (Alfano, 1971, 275). Indeed Watson agrees with such a mutual bond between the client and carer, defining a "helping-trust relationship", (Watson, as cited by Wesley, 1992, 112) as one of her ten-caritve factors in effective client management. Johnson also argued that this relationship should be vital to successful management, revolving around behaviour remodeling of the client towards a healthy lifestyle (Johnson, 1980, 54).

Swanson (1991, 163) in her theory of care acknowledges the significance of the carer-client relationship when describing her five caring processes; "knowing, being with, doing for, enabling and maintaining belief". "Knowing is avoiding assumptions, and striving to understand an event as it has meaning in the life of the other" (Swanson, 1991, 163). "Being with", is being emotionally present to the recipient. "Doing for" entails doing for the other what he or she could not do for him/herself. "Enabling" is seen to be

the facilitation of the client to his or her full potential, while "maintaining belief", is understood to be the sustenance of previous belief structures in a time where belief (or hope in oneself) is threatened (Swanson, 1991, 163-165). In an holistic paradigm, this model of care offers a flexible and empowering bond between carer and client, where "our patients (are provided) with self care skills and hope for a greater quality of life in a true partnership with us" (Sommer, 1996, 1241).
Working with this model in mind, Chipman (1991, 173) identifies some chief concerns of the client-carer relationship, where the carer should "ease psychological discomforts such as grief, fear, anxiety, or depression; and to provide a calming, soothing environment".

Nursing researchers at Burford found that the characteristics of "sensitivity, trust, control, mutual understanding, working with, and concern" in the carer promoted the health outcomes of; "effective care, meeting and developing the needs of the community, and innovative practice" (Johns, 1991, 1093). It was found that:

> "Without sensitivity it is impossible to develop trust. With out trust,
> it is not possible to establish relationships based on mutual understanding
> (and) mutual understanding is the basis for working with patients"
> (Johns, 1991, 1093).

A twelve-month study in Canada found the importance of a trusting and mutual carer-client relationship on overall health outcomes. The study in which 21 physicians and 265 patients were involved (presenting with headaches from various aetiologies), discovered that the strongest independently correlating factor with a good outcome for the patients was simply the opportunity to discuss the problem fully with the doctor at the initial consultation ($p<0.05$). Medications, referral to a specialist and investigations were found not to have any significant correlation (Headache Study Group, 1996, 285-294).

This same conclusion was reached by an American study designed to explore the efficacy of placebos in patient management. The study's results found that there was a

significantly increased chance of a placebo response in the client if the doctor prescribing had a 'genuiness, a warmth, was sincere, accurate and empathic. (Jospe, 1978, 37).

This same significance to the final health outcome of a client regarding the nature of the carer-client relationship can be seen inversely, when a mutual relationship could not be formed: A study focused at client responses to care found that the leading reasons for clients leaving their current care treatment was "not enough time spent with", the carer was "not friendly", and "questions weren't answered honestly or completely" (Greenfield, Kaplan & Ware, 1985, 522-523).

Macrae goes so far to remark that "...our (the carers') thoughts and emotions are not confined within us...if we are upset, anxious or in a negative frame of mind we will affect the patient adversely" (Macrae, 1987, 44). It is clear then from previous research that improved client outcomes result when a therapeutic milieu based around trust, mutual problem solving, and sensitivity forms between client and carer (Spiegel, Bloom, Kraemer and Gottheil, 1989, 890).

Social Support

In viewing the holistic nature of the client, the effects of social networks on patient perceptions, and ultimately health state have been well established. In Scandinavia and the United States, studies up to twelve years in length have been performed (involving around 35,000 people) where it was found that social isolation approximately doubled mortality rates, regardless of other risk factors such as high blood cholesterol levels, smoking, drinking or obesity (House, Landis, & Umberson, 1988, 540-545).

In this study four variables of social interaction were specifically looked at (marital status, contact with extended family and friends, church membership and group affiliation.). A good marriage was shown to be one of the most important health promoting factors. Even having a pet was found to "reduce stress, lower blood pressure,

reduce physician visits, to independently lower cholesterol and be a strong predictor of survival following an acute myocardial infarction" (Anderson, 1996, 441-442).

Pelletier found that people who have a strong degree of social support were found to have lower incidences of heart disease, cancer, absenteeism and shorter hospital stays. (Pelletier, 1992, 345-58). On the other end of the social spectrum, social marginality was found to be associated with a higher incidence of heart disease, cancer, depression, hypertension, arthritis, schizophrenia, tuberculosis and overall mortality (Pelletier, 1992, 345-58).

Sommer ruminates in the Australian Family Physician that the "burgeoning number of support groups suggests a need that may be reflecting the collapse of traditional family support, such as extended family." (Sommer, 1996, 1243).

This unique need for the individual to be supported by social networks was echoed in the research findings of Ruberman, Weinblatt, Goldberg, & Chaudhary, (1984, 552-559), when in a study involving 2320 male survivors of AMI they discovered that social isolation and high levels of stress quadrupled an individual's mortality rate outside of physical factors and access to medical care.

Ryden and Knopman in their research into effective client management in the cognitively impaired elderly found that "interpersonal interventions and adjustment...based on an understanding of social developmental factors may offer greater promise of affecting mood state than a medical regiment with a psychopharmacological approach" (1989, 57). The significance of significant others in the ability for the client to find a psycho-social balance in life has been well documented, and it is this importance that must be echoed in client treatment.

Empowerment/Disempowerment of Care

Green (1991, 613), argues that although great advancements in health technology and the physiological pathway of disease are being discovered, clients are still becoming more detached from their own health. She argues that through an;

> "unrealistic cultural belief in medicine and in physicians... patients expect an instant diagnosis, an instant cure, an instant relief, an instant quick fix...not realizing that the mysteries of physical disease and mind-body interaction far exceed the limits of the bio-medical model and the ability of medicine to treat a problem" (Green, 1991, 614-615).

Clients have consequently found themselves depending on a medical system that they don't necessarily understand for their own health needs, rather than promoting health-supporting behaviors. Thomas (1977, 43 – 44) supports this belief in his critique on our modern day health state and it's perception of itself. He states that;

> "Nothing has changed so much in the health-care system over the past twenty-five years as the public's perception of it's own health. The change amounts to a loss of confidence in the human form. The general belief these days seems to be that the body is fundamentally flawed...always in need of support by health care professionals".

Peterson (1996, 30), looks to the traditional (bio-medical model) model of health care as a strong reason for change, stating that the bio-medical "health care system disempowers patients by telling them what to do".

Barsky (1988, 78) agrees when he notes that although general life span is increasing and infant mortality rates are falling, more people are reporting ill health than ever before.

This is argued again by Green (1991, 164) to be the result of self-responsibility being taken from the individual in terms of health promotion.

This point is surmised well by the late Dr Norman Cousins who stated that "...up to 90% of patients who reach out for medical help are suffering from self-limiting disorders well within the range of the body's own healing powers". (Cousins, 1985, 31).

Illness can be observed as a time during which the individual loses his or her ability to control or manipulate life occurrences; atleast to a level that he or she might normally feel comfortable with (Peterson, 1996, 30). Helplessness, frustration and hopelessness are all powerful emotive forces that result from such a time. These emotions, argues Sommers are exacerbated in a medical system that can render the individual ill equipped to iniate preventative measures of his or her own (Sommers, 1996, 1241).

These negative 'mindful' states have a corresponding effect both on the course of a disease state, and on the ability of the client to utilize his or her own natural defenses to combat such disturbances in their health state.

Many studies have demonstrated the impact of stress or anger on the course of various disease states. One such study, reported in the New England Journal of Medicine found a 'dose – response' like association between respiratory illness and psychological stress (Cohen, Tyrell, & Smith, 1991, 309-322).

This association was also found to be true even in genetically determined disease states, such as asthma, diabetes and ischaemic heart disease (Klinnert, Mrazek, & Mrazek, 1994, 51-61. Surwit, Schnieder, & Feinglos, 1992, 1413-1422. Dembroski, Macdougall, Costa, & Granditis, 1989, 514-522). One particular study even found that stress could even effect the activity of RNA, thereby effecting genetic expression. (Glaser, Kennedy, Lafuse, 1990, 707-712).

Care aimed at redressing such demoralising responses in the client and providing a sense of control is seen to be most beneficial to orientate the patient to regain control over his or her own health state (Green, 1991,165). Research has shown that those patients who are allowed a greater degree of control over their own health care have: "A greater sense of control over their illness, better health outcome, a more rapid recovery, and greater compliance with the treatment process", (Cousins, 1989, 41).

A central tenant of treatment could be the belief in the body as the greatest force for healing, and the role of carer is to help the client access this resource. Indeed Aasen (1987, 20-28), and Berkowitz, Waxman & Yaffe (1988, 620-624), agree that "offering choice and more control over the environment" (Wells & Singer, 1988, 28) is paramount for empowering and effective care. Beisecker (1988, 315), adds that " providing sufficient information from which the client can make informed choices" is fundamental to the process of empowerment.

Human beings exist in a framework of society, a constant interaction, with external stimuli under the blueprint patterning of cultural law. However, the unique conscious ability of the individual allows him/her to extend beyond cultural patterning and make creative, innovative and independent decisions on his or her own. As cultural meaning is often the crude riverbed of subjective thought, it is necessary to view the client in culturally relevant terms, as situated meaning must be achieved, and will allow a better understanding of the client and his or her dimensions of being, but this is by no means the definition of the individual.

Summary

Health is not a simple disturbance in social or cultural forces. The client exists in a complex field of physicality, emotion and mindfulness. Thought can be as instrumental in healing as the physical properties of medicine and visa-versa. The placebo effect is an excellent example of such; particularly relevant as it has been seen that the potency of the effect is dependant on the basis of carer – client relationship. It is at the least highly

interesting, that perceived trust and sensitivity in the carer are some of the most strongly synergist behaviors in this psychological phenomenon. And indeed in the process of effective and long lasting care, a trusting and mutual relationship between carer and client must be achieved for truly empowering and efficient care. Treatment is afterall not just the abatement of symptoms, but a move in behavioral, educational and physical ways towards a state of well-being. The individual must be set on a spectrum of potential ability. Illness could then be defined as a state that negatively impacts upon the movement towards that persons' ultimate potential ability. As the individual fears, desires, goals and dreams of each person differ, so obviously must the journey toward empowerment and achievement. This understanding of the whole person must be aimed at perceiving the client in their own situated meaning, in their own cultural setting, in this way the carer is both counselor, community mediator and physician. In this way also, in understanding the needs of the individual, the needs of the community are also understood, and care should ultimately be aimed at using the powerful community assets of the individual in successful management of the client. Most importantly, the client must be highly involved and aware of his or her own treatment. Otherwise the client will find themselves on the blind crutch of pharmaceuticals or painful regimes, in a world of superstition and limitation. As the view of care in this study is believed to be the empowerment of the human spirit and the finding of a homeostatic balance between mind, body and soul, such a dependence is unacceptable in the course of aiding individuals on the path to wellness.

Although the importance of social and cultural forces in determining health has been well documented in past literature, the exact nature of influence has not been so readily mapped. This study was undertaken in order to explore this area of client meaning, and to demonstrate any vector of influence.

Chapter 3
Methodology

Introduction

This chapter starts with a general discussion of then research design, and goes on to elucidate the sampling procedure, data analysis, ethical considerations and validity of the study.

Methodological Framework

This study utilised a qualitative design, with a grounded theory approach as the focal structure. As the study's aim was to explore relationships between different social perceptions of illness, and consequently the lived experience of each subject, this design seemed the most specified for the purpose of the study.

Glasser & Strauss (1967, pp.36-37) define the grounded theory methodology as a study intending to "examine relationships within a particular study field, with the aim of delineating a theory or semi-causal/causal explanation of the study phenomena". Although true causality is difficult to prove (and indeed is not the aim of the grounded theory methodology), the grounded theory design allows for a hypothesis of causality to be formed for later research to verify.

The grounded theory research methodology has at its heart the formation of an analytical theory that can explain, "predict and explain behaviour" (Glasser and Strauss, 1967, 3), and is primarily a sociological tool for deriving meaning from differing human responses to similar stimuli. It was for this reason that the design was considered as ideal for the purpose of the study.

A constant-comparative method was used to achieve data analysis (Strauss & Corbin 1990), as data was continually been critically analysed for repeating patterns or themes, and compared for current literature trends.

Subject Setting and Data Collection

The study was performed on past and present students at Avondale College's School of Nursing, in a familiar and comfortable setting to the subject. All interviews were audio-taped, and consisted of eight standard questions that were designed to allow participants to speak about a time when they were ill, and elaborate about what happened.

Mechanically recorded audio-tapes were preferred as data reliability and data collection was facilitated more easily, with less chance of error in re-interpretation of data. Baker, (1986, 7, as cited by Steed, 1995, 18) stands in favour of mechanical recorded audio-tapes, when he states:

> "The inspection and reinspection of such records provides an important basis for the methodological rigour of qualitative analysis".

Ten participants were interviewed before saturation was achieved, and each filled out a small questionnaire (detailing subject details, such as age, marital status, etc – see appendix C), read a cover letter (see appendix A) detailing the nature of the study, and completed a consent form (appendix B).

The interviews were structured around eight pre-designed questions, but remained flexible enough to enquire about other applicable responses, and to accompany subject deviance (Polit and Hungler, 1993, 201-2). Each subject was interviewed once formally, with each in-depth interview lasting from ten to twenty five minutes.

The interview questions (which constituted the primary data collection device), that were used were as follows;

1. Have you or a family member ever had a serious illness while residing in Australia? What action did you (or family member) take to become well again?

2. Do you believe your (or family member's) health care needs were adequately understood by your health care professional(s)?

3. Do you believe your (or family member's) health needs were adequately addressed by your health professional(s)?

4. What do you believe was the most important factor that promoted your (or family member's) recovery?

5. What was the most debilitating part/aspect of being ill for you (or family member)?

6. What role did your family/friends play during your illness/recovery?

7. Do you feel completely recovered from your illness? If not, in what way do you still feel unwell? (or: Do you feel that your family member has completely recovered from his/her illness? If not, in what manner is he/she still afflicted?)

8. Do you have any suggestions about ways in which your care could have been improved?

Each question was designed to investigate parts of illness and the individual's life (that affected his or her response to illness) in separate ways or vectors, and were tailored so that each could possibly 'spill' onto another. This was thought to allow more possibilities for subject data to emerge (through more prompts), and so that the eventual triangulation

and analysis of subject responses could be more easily facilitated and causal or semi-causal relationships could emerge early in coding.

As data was increasingly hard to find, allowances were made for the subjects to elaborate on a family member's illness instead of their own if need be. This gave a greater access to data, at the possible cost of objectivity or accuracy of the information. The questions were tailored to be as open ended as possible, with the subjects thoughts and elaboration being sought after.

Sample

A convenience sample of 10 students, chosen from the Avondale School of Nursing and Faculty of Health were recruited. Diversity in ethnicity, age and sex were preferred in sampling , but through the rigours of sample selection, some bias was incurred. The range of subjects details included (names are assumed):

Table 1. Demographics and Social Characteristics of the Sample

Name	**Age**	**Sex**	**Marital Status**	**Country of Origin**	**Immediate Family Size**
John	21	Male	Single	Philippines	5
Linda	20	Female	Single	Australia	2
Daisy	23	Female	Single	India	4
Cleopatra	26	Female	Single	Sri Lanka	4
Kate	24	Female	Single	Australia	4
May	39	Female	Married	China	3
Monica	23	Female	Single	Columbia	5
Petra	24	Female	Single	Australia	3
Isarella	32	Female	Separated	Fiji	4
Jean	48	Female	Divorced	Australia	4

Through hardships in the selection criteria, and the availability of willing subjects, an obvious bias towards single, younger women was incurred (as this represents the larger demographic portion of the study's setting). Not enough variance could be seen therefore to allow for adequate cross-comparative study when viewing marital status and the effect on social support or overall health outcome. The same was true with age and gender.

However, a representative mix of ethnicity was achieved, that allowed for cross cultural comparison within result themes.

Interview Process

In conducting the interviews, the significance in being aware and appropriately manage possible sensitive and emotionally sensitive information was of importance. A guarantee of confidentiality was given and a trusting rapport was built with the subject before the interview.

The opened ended questions of the study vehicle allowed for in depth responses, that was encouraged by reflective listening, and showing an interest in participant responses (Deploy & Gitlin, 1993, 198).

After the interview, each participant was further debriefed for about ten to fifteen minutes, to assure that the participant was not uncomfortable or still emotionally present in his or her responses.

Data Analysis

The data was analysed by a constant comparative methodology, (Glasser and Strauss, 1967, 101), whereby data was continually critically appraised for repeating theme clusters in order to generate an underlining sociological theory of action.

Theme clusters gave rise to repeating patterns of similar aetiologies, and pointed to more specific reasons or variables that had affected the data. A theory of relationship could then be formed.

Analysis of data mainly consisted of coding; which included

- Labeling essences of data
- Identifying patterns and individual themes within the data.
- The formation of core variable(s) (instrumental aetiologies of phenomenon).
- The formation of the grounded theory (Streubert & Carpenter, 1995, 108-113).

Glasser and Strauss (1967, 105), advocated the importance of constantly comparing data when data is received by outlining the following steps of data analysis: They advocated that one must compare incidents applicable to each category, and thereby label what is seen to be the 'essence of data', this enables "the analyst to start thinking in terms of the...dimensions (and) conditions of each category" (Glasser and Strauss, 1967, 106). Secondly, one must integrate categories and their properties (identifying patterns within categories), and thirdly, the theory must be 'delimited', or reduced of text, and variables, so that the 'core' variable remains. With these most basic of relationships now evident in the data, the theory of causation or semi-causation can be formed.

Current literature was also compared to subject responses, so that the amount of data (now in the form of theme clusters) could be prioritised and the concept of the theory modified and finally integrated. This added step served to direct the focus of the new theory, so that the grounded theory could be justified in its existence (Streubert & Carpenter, 1995, 113).

In keeping with this methodology, and after some interviews and a modest literature review was conducted, some further questions were generated for future interviews so that a greater dimension of scope of the study could be obtained, and to refine current investigative techniques (Glasser & Strauss, 1967, 107). Again in keeping with the constant comparative methodology, the interviews were continuously transcribed and coding commenced throughout the whole data collection process, so that the data was constantly being analysed during the process.

Researcher Bias and Presumption

When viewing the data it has was important for the researcher to remain in an unbiased frame of mind, so not to lead data trends in a particular direction, or to misunderstand subject phenomena. This was essiental both in the data collection stage of research and the coding stage. Subsequently, additional time was taken in order to ensure objectivity. Strauss and Corbin (1990, 76) surmise this need well when stating; "there is a need to go beyond our assumptions, experience and the literature in order to open up our thinking about the phenomena we are studying".

It was difficult at times to allow increased open responses to questions or further elaborations of responses without necessarily leading the subject. When further elaboration was needed, the researcher tried as much as possible, to find appropriate prompts without suggesting one particular response over another. This was mainly done by reflective listening and the repetition of several key words from the previous response, which usually resulted in a more specific and relevant response. Such an example of an obscure or less specific response was:

Question: ...What do you think what was the most important part of actually recovering from the illness?

Daisy: Recovery. I would have liked more rest than I actually got. I think I would have maybe recovered better if I had more time off work, because you get your sick leave or go to doctors during acute periods but there is a time when you are recovering (when) you need time off work. But you just sort of get pushed back into the workforce and not completely well. I think (that in terms of) recovery if I could have had more time off work it would have been good.

Daniel: In your recovery, do you think if you had to have a look at things like antibiotics, the time off that you had or perhaps just the help that you

got from family or friends or anything like that what do you think would have helped most in just shaking off that feeling or that infection?

There was an expectation that the individual's responses to illness would vary quite considerably (especially between ethnic backgrounds), and concomitantly, it was expected that a widespread list of possible illness that subjects had experienced would be received, as no definition of illness was considered in the subject selection phase of data collection. This was intended to bring out the possible social impact of illness in the data and not to exclude or limit illness into a 'medical' or 'surgical' frame of mind. The only definition of illness in selection criteria that was considered was 'a time in your life that your life was affected by ill health'. This openness in criteria allowed a greater degree of scope and availability of subjects. As a result, selected individuals were heard discussing illness from the common cold to cancer, to epilepsy and a termination of pregnancy. The following table illustrates the variance in subject responses:

Table 2. Characteristics of the Individual and Nature of Illness

Name	**Individual Suffering**	**Illness Recorded**
John	Friend	Terminal Cancer
Linda	Grandmother	Terminal Cancer
Daisy	Herself	Viral Infection
Cleopatra	Herself	Termination of Pregnancy
Kate	Herself	Epilepsy
May	Son	Viral Infection
Monica	Brother	Dislocation of Knee
Petra	Herself	Chronic Immune Deficiency
Isarella	Herself	Ectopic Pregnancy
Jean	Herself	Chronic back pain

It was also expected that the level of knowledge (and therefore possible health empowerment) would be higher than normal (compared to people of the general public), as all subjects were training or have trained to become registered nurses. This was seen to be the result of knowledge and experience imparted by being involved in the health profession, aswell as an increased need for proactivity in terms of health promotion.

It was found that once several interviews were conducted, additional questions were added, concerning suggestions of improvement of care. This was done in order to counter a certain lack of depth in previous responses and to inquire about possible retrospective solutions.

Validity of Study

Validity was ascertained by several methods; initially some subjects (Linda, Kate and Petra) were revisited to assure clarity and objectivity. This was done to ensure the clearness of responses in the transcription process, to guarantee themes inferred from subject data were sound, and to explore any new information that may have been given on retrospection. No additional material was given on revisitation, and all three subjects agreed that what had been transcribed accurately described their lived experience.

Validity of the study was also maintained by the guidance of the researcher's academic supervisors, both experienced in qualitative methodologies and familiar with the grounded theory approach. The researcher's two supervisors served to guide the process of research from its formative stage (in reviewing appropriate methodologies for the study's design and formulation of the data collection vehicle), throughout to data analysis and eventually formation of grounded theory. A peer review at an academic colloquium (which served to present information gathered, trends found and methodological concerns) enabled questions to be fielded, scrutiny by peers, and further guidance offered.

In addition, a personal field journal was kept so as to record notes, feelings and interpretations throughout the research process. This enabled the researcher to obtain a certain degree of retrospection to clarify ideas in the from of writing. This means of notation enabled an accuracy of supposition to be made, especially in the final period of the study's life (when such notation helped lapses in memory).

A qualitative methodology was valid for the study's purpose, as the research focused on the lived experience of each participant. The grounded theory approach was also deemed to be the most valid of research methodologies, as the study's focus was on the sociological tensions and vectors of forces in an ill person's life, and how these correspondingly help in the individual's eventual recovery.

As the grounded theory formulates an empirical theory explaining subject behaviour, it is important to note that the theory's scope only extends to the range of the subject phenomena (as it is this data that the theory is formed by), and other extrapolations of the theory to extend other circumstance is somewhat baseless, without further testing. However, it is hoped that the theory may be of use in future studies when developing a conceptual framework from which testable hypotheses can be constructed. This inclination will be discussed later.

Ethical Considerations

The need for ethical concern in the study's methodology is important in order to balance scientific discovery with the potential risks to participants (Morse, 1991, 191). As emotionally sensitive and significant information was discussed in the interview process, the importance both of anonymity and confidentiality was paramount. Consent was firstly obtained from the subject after they were informed of the study's nature, length of time the interview would take, and the steps that would be taken in order to guard their confidence. Assumed names were given, and the subject was reassured that all documents, transcripts and tapes would be kept safe in a locked cabinet until destroyed. The participant was then given the researchers mobile phone number, and advised that

they could withdraw from the study at any time they wished, and that the data that they gave would be synthesised into a academic thesis, with the possibility of further publishing in journals. Each subject was also advised that they could view the final material if they wished. All subjects accepted the terms of agreement and willingly volunteered to the interview process.

The proposal of the study was drafted and submitted to Avondale College Human Research (HRE) Committee for final approval and was accepted with changes being made to the notation of consent and confidentiality.

Chapter 4

Results

Introduction

In this chapter, the results of the study will be presented in several sections relating to the 'essence' of the data found. These general essences of the data were found to delineate a separate (but no less equal) force or stressor on the individual in his or her response and overall adaptation to illness. Within each category of 'data essence' there were found to be sub-themes that added to the meaning of that particular response..

The general essences of the data were:

- Initial response to illness
- Carer-Client relationship
- Social Support
- Overall Health Adaptation

Each essence with it's sub-themes will now be discussed.

Response to Illness

All participants (n=10) sought traditional medical treatment as their primary vehicle of treatment. In an emotive sense, initial feelings to the discovery of illness were loss, denial, anger, grief and fear. Additionally, most felt overwhelmed by the experience, as seen by such responses:

Isarella: I was depressed...I thought what else could happen to me.

May: I just couldn't cope.

Jean: I was really disappointed and I got really frustrated.

Linda: She didn't tell any of her family for about a month

Two respondents (Cleopatra and John) stated the hardest thing about being ill was infact the emotional strain that affected their lives, or need to adapt, as seen by the following responses;

Question: What was the hardest part of being ill for him?

John: I guess up to a certain level he would have to be emotionally sad that he would never be able to experience that what everybody else experienced in the future – grow up, get married, stuff like that.

And;

Question: What was the most debilitating part of the illness for you in this experience?

Cleopatra: Emotionally dealing with it. It was more emotional.

This general feeling of being overwhelmed by the need for health and/or life adaptation was seen to be experienced in most of the subjects. A lack of independence and a new lack of control over their situation exacerbated these initial feelings. On two occasions these feelings of loss overran into the financial arena of the subjects lives, as their illness impacted on the ability to work and earn money:

Question: What do you think affected you the most?

Daisy: For me it was just the fact that I was sick, I didn't get paid and so the hardest part in the end was coping with the fact that I didn't have – I couldn't financially cope because I couldn't work…It really, really made it very hard.

Isarella also agreed with this loss as having a major impact on her life:

Isarella: …and the fact you know you can't work and also during that time I wasn't allowed to work because of how big the surgery and so I had financial problems which added to the problem and depression…that to me was the pits.

The change to everyday life and the loss of independence coupled with a fear of embarrassment was felt by Linda's grandmother:

Dan: What was the most debilitating part of being sick for her?…

Linda: Probably just not being able to do what she would like to do – like getting around…because she was on the steroids she got all puffy and stuff, so she was embarrassed to go out in public…Just not being able to get around because she was very carefree and loved life and she couldn't do a lot of these things.

A lack of control and fear of the unknown was also seen in Petra's response;

Petra: Also, just the worst part was not knowing what was wrong with me…having experts milling in, but still no-one coming up with a solution.

These feelings of loss and fear show the degree of influence illness had on each individual's everyday equilibrium. This response would be the start of an adaption process that started with the "will to get better" (Isarella), and was proceeded by the need to seek medical attention. Ultimately, the end result of this healing process would be dependant on factors such as an empowering carer-client relationship and an adequate social support network to lean on.

Carer-Client Relationships

After seeking medical treatment, the participants found themselves involved in the sometimes lengthy treatments by their primary care givers. Overall some actions and approaches of the carer were seen to be empowering to the individual on his or her path to wellness, and others only exacerbated feelings of loss, and continued the passage of illness.

Empowering care was seen to be affected by a number of variables or traits in the carer-client relationship that will now be discussed.

Holistically Minded:

The ability for the carer to view the client in a social scope and a lateralness of mindset was found to be attributive to healing. This can be seen in such responses;

Question: How do you think she viewed the doctors and the nurses and people like that helping her?

Linda: I think she thought it was really good they helped heaps and they were really caring to the family also, not just to her.

And;

Cleopatra: I made sure it was a female G.P because I was more comfortable that way and I think she understood how uncomfortable I felt because she asked me about my background and things like that, so she was really helpful in that sense.

Conversely, Daisy, Kate, and Isarella found the care they received to be disempowering from the very lack of a holistic, or open viewpoint; these subjects experienced other adverse symptoms or a continuation of ill health as a result.

Question: So you were upset that they didn't look at the bigger picture?

Daisy: Yes. They were so preoccupied with one thing they didn't really think of how it can affect me if I am having a longer course of anti-biotics…I remember being really upset that neither GP really thought about giving me some sort of , or encouraged me to take any acidophilus or anything like that, because I ended up with thrush and I was upset that they didn't tell me that I could do something so I didn't get it.

The same was echoed by Kate's comments;

Kate: …Drugs don't work the same for everyone, and it actually had adverse effects and increased my fits, so I was having up to one every ten minutes on the drug, and they (the carer) didn't seem very responsive about it and when my parents approached them to say "look it is not working", they actually increased the dosage as I recall, and you know everything stayed the same. I didn't get better at all and so we actually had to change specialists because we didn't feel they were doing anything to help and weren't open-minded enough to try a different approach.

Jean stated in accordance:

Jean: ...I think the doctor seemed to have no understanding...They just didn't go into my family background all that much, although I did say I lived on my own, and I was having trouble...There was no suggestion of how I could get help around the place.

An ability for the carer to view the individual in his or her own situated meaning and with a latitude of flexibility therefore was found to be a major variable influencing the individual's path to wellness.

Informative, Supportive and Communicative

The ability of the primary care giver to be easily communicative, supportive and informative was beneficial to client health. By presenting these traits, it was found that the carer and client entered into a mutual relationship of information sharing, and trust. This was found to empower the client by allowing him or her to be involved and informed in his or her own healing process. Subsequently feelings of fear and a lack of control over their own environment were dispelled and replaced with hope, and purpose.

Jean describes this experience when comparing her physiotherapist's care with her doctor's;

Jean: They explained a lot to me that the doctor just didn't explain and they were able to give more information which helped me to feel less threatened and they gave me time and they explained the whole process so that I would know that there was going to be an end to the pain.

The informative carer can be seen to be empowering by granting the ability for the client to visualise his or her own healing. As a result, hope is formed, and a more positive outlook is enabled.

Communication between the carer and client is obviously essential to adequately enable a trusting and mutual bond to form. This was well demonstrated by;

Question: Do you think your doctor adequately understood what the problem was, or where you were coming from?

May: Yes, yes he did because I could communicate with him well and he gave me some information in how to take care of him, observe him, and if anything seriously happened to take him straight away to see him again. My doctor was very good.

Monica elaborates further on the supportive, informative (and holistic) nature of meaningful care when stating:

Monica: As well the doctor, he was great. From the beginning he said: "look this is what's going to happen, the recovery process, like it's going to be hard, but you can do it", and he said it's not only your body, but it is also your mind that's got to work – he was really great about it.

The importance of an interested and supportive carer was also reinforced by the additional comments of Petra.

Petra: The follow up through (the doctor) was pretty good and he makes sure that I'm coming back to him and I can speak to him whenever I want, email in, stuff like that.

John confirms this importance when he stated that he believed the "support network that the staff was offering…with regards to his (friend's) stay in hospital" was the most important factor that helped in his friend's care (and eventual emotional acceptance of a terminal illness).

As the importance of a supportive, informative and communicative carer-client bond in influencing positive adaptation processes to illness was found, conversely the opposite was true; leading to negative adaptive responses to illness. Cleopatra, Kate, Isarella and Jean complained of the nature of care being a negative factor in their healing experience.

Cleopatra found herself estranged from any personalised direction of care that was resulted by the detachment of medical staff and attributed to a loss of identity;

Cleopatra: I think the actual GP in referring me to the actual clinic was fine, but I found that the clinic was basically like a factory line, you go in, get this done, you go out, get changed, you go into theatre …(and) not following through orders and generalising and stereotyping.

She also complained that one of the most disempowering process of her illness was the lack of control over her own treatment and the disbelief of the medical staff to her complaints:

Cleopatra: Just the whole situation of having the laughing gas and having four nurses holding you back and the whole procedure and the thing that really hurt, annoyed me was (the) disbelief in the medical staff and the situation.

Isarella stated that she thought that the "doctor was very ignorant…(he) didn't tell me anything".

Kate, Petra, and Jean share Cleopatra's feelings that detachment by the treating medical staff led to generalised feelings of loss and estrangement. Here we see care that does not affirm a mutualism of forces, and leads to the client not feeling in control of their own experience.

Petra: I didn't like the amount of people that came to ask me questions, different people, students and stuff like that. It was too many people. I felt like a strange person…A particular student came up to me and said "you know they really don't know what it is (the illness)…and all you've got to go by is these people, and they're like Gods, I mean you hear this from this, and it totally threw me and I didn't know what was going on. Also they kept walking in with these face masks…and the next day they wouldn't, and then the next day they would…nothing was consistent…I think they could have been more thorough in the way they behaved there.

Jean's experience working in the health profession, actually made her feel already reluctant to seek recommended care as depicted in her statement;

Jean: I have heard a lot of nurses make negative comments about patients being difficult and they have been so rude and made such negative comments about these patients that I refuse to go into hospital.

Question: So that was threatening aswell?

Jean: Yes.

Jean continued on to say that even her treating doctor was viewed not to be interested in her problem.

Jean: …either assume that the doctors thought I must have been getting help or they were just not interested in me.

Kate stated that her initial doctor was not informative at all, and that she did not have any opinion in her treating regime. This she stated would contribute to the treatment not working, and her eventual move to another specialist;

Question: Did they ever discuss what that (her treatment – more specifically her EEG) was about?

Kate: No. They didn't actually tell me why they were doing it.

Question: Were you wondering why?

Kate: Of course yes. You don't really ask those things when you are nine years old, you just do what you are told. I was sent home. That was the end of it…I think that it is a major factor that people should speak to children about what is happening to them exactly, don't hide anything…

As previously mentioned, the carer-client relationship was found to be highly influential in overall health adaptation. Simple carer traits such as understanding, interest and support were found to be far more health impressing than the actual treatment itself (such as medication or treatment regime – which was only mentioned three times as being influential to recovery).

Social Support

Another factor that influenced overall health outcome was seen to be social support. It is important to note that all subjects sought social support and visited either family or

friends (if one was not available or less supportive, then the other would be utilised more heavily). This demonstrates the importance of significant others to the individual in times of need or change. Even though all varieties of support was utilised, family was seen to be most instrumental in helping positive adaptation to the experience of illness.

Subjects that had less support generally found more trouble in overall health adaptation, as seen by;

Daisy: I had a few friends around which was good – but I didn't have any family around so I didn't really have that kind of support to lean on which means – it just makes it harder because you feel like; oh you're sick and you are a bit alone, so it would have been nice to have family around – friends did help, that was good…but you need mum around to pamper you a bit.

Kate: I got laughed at by most of my friends and actually lost a lot of childhood friends because they didn't understand what was happening…(I was) in fear of being laughed at, something going wrong…people still knew me at school to be that freak…Well the family was very, very supportive. At home they didn't treat me differently and that was very important.

Isarella: I think family members around would be a big, big help… I think at times like that, it is important to have family members around or people that you can trust that can help you at short notice.

Jean: Actually, part of it, my parents live interstate and I would ring my mum up a little bit. They played a minor part…I suppose I felt very much alone.

Support was found to grant a sense belonging and a greater capacity to cope in the face of change in self-identity, and consequently subjects who had a more extensive network to draw upon were found to have a positive health outcome. Examples of this psycho-social influence to health was seen in the following responses;

(in response to John's friend's family caring for him while he had a terminal illness)

John: Like I said, they were his support network and I think that was what he needed at that time – just to be comforted and reassured at that time, that his family was there when he needed them – sort of gave him a feeling of belonging.

(In response to her parents caring for her terminally ill grandmother)

Linda: She was really impressed with that - It gave her hope that people really cared about her.

Question: What do you think was the most important factor in helping your son's recovery?

May: I think the one could be having adequate medical treatment...and the second, the mother or parent had to be with him to take good care of him and make him feel secure.

Peers were also instrumental in defining crucial self image, as seen by;

Kate: So they sent me away to a different school where no-one knew my past and it was totally very understanding, giving me some independence and trying to get better that way and get more confidence in myself which worked.

Question: Excellent. Do you think that gaining a new image of yourself among your peers was the most important thing?

Kate: Yes. I think so, and because they had been briefed on what had happened, they where prepared for what I was like.

Question: In terms of recovering from the experience, obviously more than physically way, but just emotionally how did you come to terms with it, what do you think was most important to you? What do you think helped the most?

Cleopatra: ...I would have to say it was my friends and the support I got from my friends and understanding and it made me realise that these were not the only values and that there is other ways of looking at the situation.

Support enabled significant others to be emotionally present with the ill individual, and thereby ease adaptation by the individual not viewing themselves alone in a now somewhat hostile or threatening environment;

Petra: Mum was always there, she was talking to me…Friends, they just came in and were doing what friends do I guess, just talking and sitting…I guess Mum was the biggest factor there. I cried with her a lot.

The ability to express feelings of fear and/or loss to trusted friends and family, and for mutual understanding to be present was also paramount, with social networks taking a counseling or mediating role during the illness;

Cleopatra: I think, like I said I am not really close to my family. I think my friends came through a lot for me and brought out the realistic aspect of it and not the value and what you should do and what you shouldn't do in a difficult situation and they helped me through it.

Question: What do you think was the most important thing that helped your brother's recovery?

Monica: I think the family, because he was very disillusioned…you see my parents and me took him to physio every morning and helped him to have a positive outlook.

Support also allowed for others to help the ill individual in achieving activities of daily living, that he or she would be unable or find difficult to do on his/her own. This additional benefit of social support was felt by Jean when she states that;

Jean: I virtually had no social and emotional support, anything like that...I just couldn't, I found it very hard to look after myself and I existed on cups of soup and continental noodles.

Isarella: I got back home the house was in such a mess I picked up the vacuum cleaner and that was exactly what the doctor said not to do, so I started cleaning up and that night I couldn't go to sleep because I was in severe pain, so I had to go down to the hospital to get some Deloxin.

Overall Health Outcome

Overall health outcome was continually judged from responses discussing feelings of empowerment and self-perceived reflections of recovery. It was found that out of ten subjects, four experienced satisfactory recoveries, four experienced unsatisfactory recoveries (where complete healing had not taken place), and two subjects spoke about friends or family members who died of terminal cancers (although in both circumstances emotional acceptance had taken place).

Jean spoke of continuing back pain;

> "part of my life seems to be...a bad back".

Petra complained of a reoccurrence of symptoms;

> "...I've started feeling the symptoms that were around when I had it. Not nearly as bad."

Isarella spoke of continued problems;

Question: Do you feel completely recovered?

Isarella: No, not really…I feel I am lucky to be alive…I don't think I have fully recovered from it.

And Cleopatra states that;

> "As the years go on it's not so hard a situation but at the same time it is still pretty difficult…In terms do you ever get over it – No. I think it comes back at you

In all four subjects, each complained of a poor client-carer relationship, with most (Cleopatra, Isarella, and Jean) also stating of limited social support.

In the cases of positive health adaptation (Daisy, Kate, May, and Monica), subjects responded:

Question: …You feel completely recovered from the illness now?

Daisy: Now yes, now yes.

Question: You have obviously completely recovered now?

Kate: Yes. When I was 14 they took me off the drug.

Question: He has completely recovered from the illness?

May: Yes, yes he did.

Question: Has he recovered?

Monica: Yes.

Table 3. Comparison of Individual Actions to Illness

Name	Response to Illness	Carer-Client Relationship	Degree of Social Support	Overall Health Adaptation
John	Shock and emotional disturbance.	Supportive, communicative.	Present from both family, friends and staff	Emotional acceptance of terminal illness.
Linda	Denial, embarrassment, and depression due to a lack of control.	Supportive, communicative and holistic.	Present from both family and friends.	Emotional acceptance of terminal illness.
Daisy	Feelings of loss. Fear associated with inability to resume activities of everyday life.	Narrow minded, but supportive.	Present from friends. Felt the lack of family members around to help was hard.	Positive, but illness took along time to shake. Health adaptation achieved but with more effort and difficulty.
Cleopatra	Fear; feelings of judgement and loss	G.P was supportive and holistically minded, however felt a keen disinterest and disbelief from medical staff in treatment, and no client-carer bond was formed.	Keen lack of familiar support, while friends and a counselor played a vital and compensatory role in helping adaptation.	Negative. Still believes she is recovering from illness.
Kate	Fear and feelings of victimisation.	**Initial G.P:** Closed minded, unsupportive and uncommunicative. **Second Opinion:** Understanding, supportive and communicative.	Friends played a mocking role that hampered overall adaptation. This teasing reinforced a negative self image that translated to inability to adapt. Change of school/place helped in forming perceived 'new' identity and allowed adaptation to begin. Family throughout were of primary importance.	**Initially:** No health adaptation occurring at all, fits were still regular and did not go away, social and mental development hampered. **Secondly:** Total health adaptation being achieved by 14 (5 years after initial treatment). Social and mental equilibria achieved.
May	Inability to cope.	Communicative, supportive and informed.	Family played a primary role.	Health adaptation achieved.
Monica	Fear and distress.	Communicative, supportive and holistic.	Family played a primary role.	Health achieved (fear still being overcome).
Petra	Lack of control and associated fear.	Uninformative, unsupportive (except for referring G.P) and threatening.	Family played primary role – friends to a lesser extent.	Negative health adaptation. Reoccurrence of symptoms.
Isarella	Depression and feelings of victimisation.	Ignorant and unsupportive.	No significant familiar or friendly support.	Negative healtvh adaptation (still believes she is still recovering).
Joan	Inability to cope and related depression.	Threatening, unsupportive and uncaring.	Little social support from any vector.	Negative health adaptation (recurring symptoms of chronic pain).

Summary

The results present some general trends and significant relationships that serve to influence healing in a number of ways. Firstly, all participants demonstrated that social support was an important part of adaptation, regardless of race, age or any other descriptive criteria. All participants registered feelings of loss or disorientation in response to illness, and all participants sought traditional medical treatment when trying to adapt to illness.

Four participants described a healing process that they defined as successful, while another four stated that full healing had not yet taken place; and two participants came to an emotional understanding of their impending mortality, when suffering from terminal cancers. Factors influenced such outcomes were a mutual client-carer relationship, that was informative, communicative and supportive in nature and social support from family and friends. Those participants who had less support or a poorer form of support, were found to have a higher chance of ineffective adaptation to illness. Participants who had a poor carer-client relationship were also perceived to have difficulty in adapting to the phenomena of illness. In this manner, quality of social support and a mutual bond between client and carer were two of the major health sponsoring behaviours in the participant's experiences. Another factor that aided recovery was the ability of the carer to relate to the client in a holistic manner.

The results of the study imply a spirituality or holism of self that must be understood and addressed in care and at the same time highlights the social nature of the individual, bound by identity to the his or her cultural community at large, and to significant others in bonds.

Chapter 5
Discussion

Introduction

In constructing a theoretical framework where social and cultural values were set in the spectrum of health and illness, it was important to view illness as a time of change. A time when there was a disturbance in the homeostatic balance of an individual's social, physical and/or emotional life. As a response to this, healing was seen to be an adaptive process where equilibrium was sought.

In the process of adaptation, it was found that there were 'internal' and 'external' forces that aided recovery. Internal forces included natural resilience to disease, self-confidence and the actual physical properties of illness, while external forces consisted of sociological and caritve factors in the individual's environment. Although this study touched on such internal issues as 'the will to get better', and depressive factors secondary to loss, its main goal was to chart the process of external stimuli that affects an individual on the path to wellness, and to demonstrate how this in turn effects the 'internal field' of a person's being.

This discussion will review the phenomena of illness in the context of the study, consider aetiologies behind participant behaviour and conclude with an empirically based theory of health adaptation that explains the process of health empowerment in a social and holistic manner.

Health and Illness in the Study

Illness was a time of challenge and change. Although the study did not explore the relevant issues that precipitated each subject's period of sickness, the resulting feelings and process were sufficiently studied to reach a satisfactory conclusion. Firstly, all participants recorded feelings of loss, of estrangement, of fear or of an inability to cope in

their normal manner. Therefore, illness was a stressor that disrupted the traditional stability of a person's life and as a result, the individual now felt alone, out of touch or exhausted in their efforts to persevere in his or her daily life.

All participants sought traditional health care measures to rectify such disturbances, and all participants depended on family or friends for social support. We can see that in times of need, the importance of significant others and the perceived role of health care allowed the individual a greater ability to endure. Social support was found to provide a sense of belonging and a greater capacity to cope in the face of changes in self-identity, while the efficacy of an understanding and interested health professional was also noted to be instrumental in healing. This innate need of the individual to seek meaningful social bonds was a major common finding of the study, and was demonstrated by the participants' reliance on the resources of family and friends and the finding that a trusting and supportive relationship with health professionals aided in recovery. This relationship was anticipated and is similar to the findings of Landis & Umberson (1988), where social support from family and significant others was shown to be a major health promoting factor in the lives of over 35,000 subjects (Landis & Umberton, 1988, 540-45). This result was found across cultures, leading to the conclusion that although culture determines the perspective in which the client will orientate themselves to illness; the needs of support and a trusting and mutual care are universal. In this sense cross-cultural comparison was important to validate common needs amongst the participants regardless of race or cultural differences.

Theory of Health Adaptation

It is through the comparative differences in responses and eventual health outcome, that a clearer picture of this adaptive process comes into focus. From the initial reaction to the threat of illness, it was seen that the adaptation process had begun and that 'external' factors such as an empowering carer-client relationship and an adequate social support network could create an environment conducive to a successful conclusion of this adaptation – which was health empowerment and healing (see figure 1. – A conceptual model of Health Adaptation).

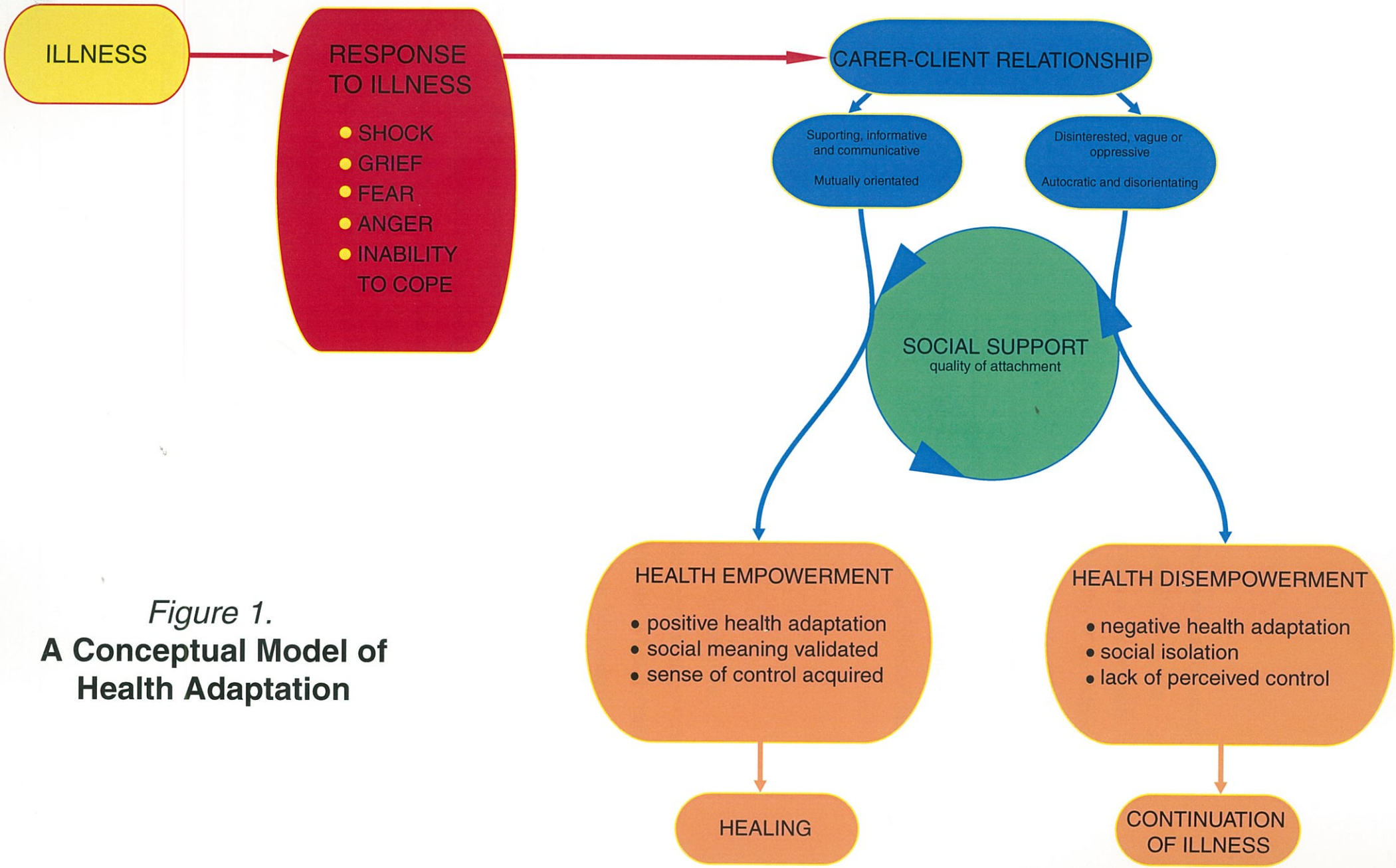


Figure 1.
A Conceptual Model of Health Adaptation

Response to Illness

The response to illness is one of loss or disorientation. The normal, everyday balances and routines of the participant's life were found to be disordered which resulted in feelings of fear, grief and generalised feelings of anxiety. In this manner the physical causation of disease can be seen to be affecting the psycho-social ability of the individual to cope or adapt in everyday life. In response to this feeling, there is an increased need for the individual to seek significant others to re-align such a homeostatic imbalance. We see initially an equilibrium shift that favours the continuation of disease. A holistic dilemma that confuses and disempowers the client not only form his or her health, but also distances the client from his or her ability to maintain hope, complete activities of daily living and most importantly, retain control.

Carer-Client Relationship

After seeking medical treatment, the participants found themselves involved in the treatments directed by their primary care givers. Care was ultimately seen as empowering or disempowering, judged on the final health outcome of the participant. When the carer acted like a guide rather than autocrat, viewing the participant in his or her situated meaning, being supportive, easily approachable and informative, care was seen as empowering. When care was not mutual, overly oppressive or controlling or not informative, illness continued. This reaction was evident for a number of reasons: The informative carer empowered the client by aiding them in visualising his or her own healing. Hope of recovery was then formed from the knowledge of action and the ability to rationalise illness. Furthermore, a communicative carer facilitated a mutual understanding between client and carer, enabling the client to interact more purposively in his or her own healing process. It was also found that a carer who viewed the client within his or her own situated meaning, with a lateralness of awareness empowered the client by utilising the individual's social environment in recovery. When suitably aligned in purpose and understanding, the client-carer relationship was a powerful force toward the end point of wellness for the participant.

Social Support

While the nature and actions of the health professional's treatment dictated empowering health adaptation, social support concomitantly influenced the ability to retain a stable and positive self-image in the face of change.

Support granted a sense of belonging, it enabled significant others to be emotionally present with the ill individual, allowed for others to help the ill individual in activities of daily living, and gave a forum where the individual could express feelings of fear and/or loss. Self-image and feelings of worth were validated or rationalised within a trusting and safe environment.

Human beings are social creatures, with the innate ability to adapt to new or changing surroundings. In times of crisis, when this ability to adjust is threatened, the participants found new resolve and control through others. The capacity of human beings to be empathic with each other, to rationalise fears and anxieties bred from the disturbance of illness and to find validity in feelings, thoughts or changes amongst others was found to be essential in the healing process, (Rogers, as cited by Barrett, 1988).

Health Empowerment

This viewpoint or rationale for healing encompasses a certain spiritual or psycho-social dimension of care, and acknowledges the principles of "kindness, concern, love of self and others and a respect for the spiritual dimensions of the person" (Watson, cited in Wesley, 1992, 112). Successful care in the study was attentive the client "developing a higher sense of self" (Watson, 1988, 43), and consequently participants were then capable of evolution in a thoughtful, emotional and spiritual sense. When the whole person was not viewed, or knowledge not imparted, or when client problems were not listened to by the carer, unsuccessful client adaptation resulted.

When care was given to the client, viewing them as an "unified whole" (Rogers, as cited by Barrett, 1988, 57), who is constantly interacting with their environment in meaningful ways, the true nature of health and illness became apparent. The individual is as responsible for making up their respective community, as the community is of making the individual and the two were found to act and react in a complex, but predictable manner, allowing growth, adaptation and an homeostatic equilibrium to exist of mind, body and spirit.

When allowed (by support or knowledge), individuals were able to adapt to illness in meaningful ways, by care that was "directed toward the nature and direction of human development" (Taylor, Lilis & LeMone, 1993, 56). The tools of visualisation and the unique capacity of humans for abstract thought, imagery and emotion were seen to be a primary mechanism in the design of wellness (Rogers, as cited by Barrett, 1988). This was seen at it's clearest when care was seen only to be directed at the mere parts of the individual, and a continuation of illness resulted.

Implications to Nursing Care

When looking at the results and final theory delineation of this study, several factors became evident that was seen as relevant to future nursing care. The importance of a mutual relationship between health professional and client was the largest contributing factor to the success of treatment. The ability of the carer to be lateral in his or her approach to client diagnosis or assessment also contributed to a positive health outcome. It was this initial phase of client contact that most participants felt that they had been 'let down' by their respective health care professional. Even the simple action of being interested in the client's plight, and thereby treating the individual as an unique entity, and not as a distant problem was found to give crucial self-meaning to the client and affirm the trust placed in both the healing process, and the health professional. One of the greatest actions of care a health professional performed was to aid the client to visualise his or her own healing; to be energised by the knowledge of recovery, and thereby feel assured of achieving it.

Illness is a time of disorientation. It could be seen that the carers' role in this time is to act not only as a force of healing, but as a compass of direction. It was seen that successful care was achieved mainly by activating the latent ability of the client to actualise his or her own healing. It is also somewhat comforting and not a little surprising that in the day of technological cures, and medical miracles, the simple importance of trust, mutual understanding and communication were found to be the most effective mechanisms of treatment.

Limitations of the Study

The greatest limitation in the study was the actual design itself. Being a qualitative, grounded theory methodology, the final conclusions of the study cannot be extrapolated to phenomena beyond the study's design. This inability to generalise is common to all grounded theory designs, and depends on more quantitative designs to prove the existence of a generalised, high range theory of causality in the public at large. The convenience sample and small sample size, coupled with a lack of variation (particular in relation to marriage status and age), also limit the study's scope. As the variation in such social structures were small, so was the ability to research into the unique nature of each structure. The study then was not able to consider the particular impact that each social bond or structure had on the phenomena of illness.

Another important limitation in the study's design is the sample setting. By basing the whole sample selection at Avondale College's Faculty of Nursing and Health, it is possible that a certain amount of homogeneity was introduced into the study. In this Christian college, it could be anticipated to expect individuals that adhere to a more holistic definition of care, or a more spiritual dimension of treatment. Even though responses varied considerably between participants, a similitude of thought among the participants based apon their current study, and backgrounds, could possibly have introduced unwanted bias into the study, and again could be seen as another limitation.

Finally, the study's approach of looking at participants only during the recovery period of illness, could have limited the available information in examining the study's purpose. By re-examining relevant issues pre and post illness, a more clear representation of adaptation could have been formed.

Recommendations for Further Research

As the study's design was a qualitative, grounded theory methodology, it is recommended that future researchers validate the theory's final findings in the community at large. In addition, further qualitative designs aimed at addressing some of the failures of scope in this study; for example a more solid investigation of the impact on health adaptation that marital status has in the life of a client.

Larger more elaborative phenomenological designs could be useful in fully assessing the lived experience of the individual, while quantitative or quasi-experimental designs are seen as ideal in the validation or proofing of the theory at large.

There is believed to be a need by the researcher to understand not just the social structures and relationships in an individuals life, or the way that these interact, but the methodology in which these compositions influence the health status of the individual. Many studies have gone about defining the importance of social structures and found statistical relationships between support and health, but not many have explored the crucial adaptive process of change that takes place in recovery. It is thought that the precept of significance in social structures to the client has already been well established, and even to what degree these structures influence the client's everyday life. Statistically researchers can vaguely predict those people who have a higher-risk of morbidity solely from the quality of social structures in the individual's life. However, the mechanism of action behind this evolvement from illness to health is thought not to be well understood. Further research into this challenging and dynamic aspect of healing is therefore recommended, and perhaps in the process a more vital and less static model of care can be implemented.

Concluding Remarks

As a first time student researcher, the process of constant comparative reflection and purposive objectivity has been an enriching experience that has allowed me to contemplate my own care practices in my professional life and view client adaptation with an added dimension of clarity and open mindedness.

It was the intended experience to highlight and examine in an interrogative way the social dimensions of client care. It is believed by the researcher that most (some may argue all) clients have within them already the resources for healing. It is through experienced care, directed at enabling the client to manipulate such resources that the most successful and efficient care can be given. This type of care has the benefit of teaching the client to empower him or herself, so that in times of future ill health, they have a greater ability to recover or maintain homeostasis. In a time when the position of future care structures are in threat from budgetary or understaffing concerns, this particular view of care is seen by the researcher to be both practical (in an economic sense) and altruistic in manner. Furthermore, as the tools of recovery are often as simple as trust, learned knowledge and support, family and friends can be instrumental in giving the most profound or efficacious type of care.

This study in no way is intended to disregard a classical bio-medical model of care, or suggest new age remedies for all physical crises. It merely suggests a better delivery of care by asking the question; by searching for disease, are we forgetting our patient?

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Participant Information and Consent Form

This study is about how people view and experience health. There are eight questions that involve you to describe a time when you or a close relative were ill.

Your responses will be audio-taped, so that accuracy can be maintained, and you will be given an assumed name in the study. The study may be published in a journal at a later date.

Here is a copy of the questions that will be asked. If you choose to participate, then you will be asked to sign a consent form, formalising your intent to join the study (see over page). If you choose not to participate, or cannot remember a time when you or a close relative were seriously ill, then please state this now.

If at any time during the study (up until the end of the year), you choose not be a part of the study, you may withdraw, without cause, and can always contact me on 0413 002 435.

If you have any questions to ask, then please do not hesitate; thank you for your time and consideration.

Questions:

1. "Have you or a family member ever had a serious illness while residing in Australia? What action did you (or family member) take to become well again?"

2. "Do you believe your (or family member's) health care needs were adequately understood by your health care professional(s)?"

3. "Do you believe your (or family member's) health needs were adequately addressed by your health professional(s)?"

4. "What do you believe was the most important factor that promoted your (or family member's) recovery?"

5. "What was the most debilitating part/aspect of being ill for you (or family member)?"

6. "What role did your family/friends play during your illness/recovery?"

7. "Do you feel completely recovered from your illness? If not, in what way do you still feel unwell?" (or: Do you feel that your family member has completely recovered from his/her illness? If not, in what manner is he/she still afflicted?)

8. "Do you have any suggestions about ways in which your care could have been improved?"

Personal Details
Interview Title Page

Name (assumed):

Age:

Country of Origin:

Years in Australia:

Marital Status:

Immediate Family Size:

Consent Form for Participation in Research:
"Health and Illness: A Socio-Cultural Perspective."

I, the undersigned give my voluntary consent to participate in the research study; "Health and Illness: A Socio-Cultural Perspective". The study has been adequately explained to me, and I have had the opportunity to ask any pertinent questions regarding the study.

I understand that assumed names will be used, to hide each participant's identity, and all data will be locked in a private cabinet until destroyed. I also understand that all information collected will be dealt as strictly confidential.

I am aware that I have the right to withdraw from the study at any time during the research process, and give my consent to this interview and the use of the information given for the expressed purpose of the study. I understand also, that the results may be published, and that if published, identity of all participants will be safeguarded.

I am also aware that if I have any complaints concerning the research study, or the manner that it is carried out, I can address such complaint to the Avondale College's Ethics Committee Secretary, Avondale College, PO Box 19, Cooranbong NSW, 2265, or Phone on (049) 80 2161.

Signature of Participant: Date:

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Human Research Ethics Committee
Avondale College
21-5-01

Mr Daniel Jones,
Avondale College.

Dear Daniel,

Thank you for your research proposal which was considered at the Human Research Ethics Committee meeting on the 18th May, 2001.

Your application for the study entitled **"Health and Illness: A socio-cultural perspective"** was approved subject to:

1. The anonymity of the participants being ensured in any written report or publications, particularly given the small pool from which participants will be selected.
2. The 'witness' signature being removed from the consent form – this is seen as unnecessary, and it may compromise anonymity if left as a requirement.

Please note that the approval relates only to the procedures as outlined in your application to this committee. Any variation or amendment to this protocol must be forwarded to, and be approved by, the Avondale College Research Ethics Committee prior to implementation.

Wishing you all the best with your research.

Darren Morton
Secretary
Human Research Ethics Committee

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