

**The Unmet Psychosocial and Supportive Care Needs of
Young Adults who have a Parent with a Non-Communicable
Disease**

**by
Samantha Williams**

A portfolio submitted to the University of Wolverhampton

for the

Practitioner Doctorate: Counselling Psychology

Award: D.Couns.Psych

October 2012

ABSTRACT

AIMS

Unmet needs have mainly been investigated with formal and informal adult caregivers and ill individuals within psycho-oncology; findings indicate unmet needs are associated with negative affective state and caregiver burden. Research relating to adolescent children's experiences of unmet needs during parental illness has, in the main, been based upon parental reports or professional opinion, yet research suggests that parental reports can downplay the effects and it is important to ask the adolescent child for their opinion. Adolescence is a transitional time in development; this may make the illness experience and subsequent needs vary from those of formal and informal adult caregivers. This thesis pragmatically investigates adolescent children's firsthand accounts of unmet psychosocial and supportive care needs when they have a parent with a non-communicable disease.

METHODS

Systematic Review

To inform the direction of the thesis and capture all relevant published literature, a comparative systematic review was carried on adolescent's experiences of unmet needs when they have a parent with a NCD, cancer or psychological problem. The review was conducted using standardized procedures and guidance from the Cochrane collaboration.

Interpretative Phenomenological Analysis

Qualitative methodology was used to investigate seven adolescent's experiences of unmet psychosocial and supportive care needs in relation to having a parent with a NCD. Participants were recruited through institutions of further and higher education.

Quantitative Research

Pearson's correlation and multiple regressions were used to test associations between unmet needs, depression, stress, anxiety and quality of life, and to determine the applicability of the revised version of the Offspring Cancer Needs Inventory (OCNI) for individuals who have a parent with a NCD. One hundred and seven adolescent children completed the revised version of the OCNI, the DASS-21 (depression, anxiety, and stress) and AC-QoL (Adult carers' quality of life) scales.

FINDINGS

Systematic Review

In the review 1479 papers were considered. Seven met the inclusion criteria, of these five papers related to cancer, one to chronic illness and one to psychological problems. Results suggest that adolescents had informational, supportive and recreational needs, and did not want to worry parents by asking them questions. The lack of hits and the disparity between illness groups is problematic in making comparisons and drawing definitive conclusions.

Interpretative Phenomenological Analysis

Four interdependent themes emerged from the data, two relating to interpersonal needs (*Information Needs* and *Support Needs*), and two relating to intrapersonal needs (*Need for*

Acknowledgement and Need to be Them-Self), each had their own number of sub-themes.

Adolescent's had a variety of needs that could be partially met through honest and accurate information, interpersonal support and acknowledgment of their caring role within the family. The interdependence of the needs indicated that the fulfilment of one need has the potential of meeting other needs. Unmet needs were comparable to those of adolescent children who have a parent with cancer; as such it was deemed that the new version of the OCNI would be suitable for use with individuals who had a parent with a NCD.

Quantitative Research

Ninety-Three percent of adolescents reported at least one unmet need. Analysis suggests that the unmet needs variables were co-dependent and correlated with depression, stress, anxiety, and quality of life. Certain unmet need variables predicted stress, anxiety, depression, and quality of life.

CONCLUSION

The findings of this thesis indicate that adolescent children who have a parent with a NCD have a variety of unmet needs, and that these are associated with affective state and well-being. It is suggested that counselling psychologists are well placed to provide psychological and needs based interventions based upon the findings within this thesis. More research is required in this area to determine cause and effect; owing to counselling psychologists working with the lifespan they would be well placed to further the knowledge in this area.

Keywords: Unmet needs, non-communicable disease, adolescence, pragmatic research.

RESEARCH REPORT CONTENTS PAGE

	Page No.
Chapter One – Literature review, theoretical framework, and thesis overview	1
1.1 Introduction	1
1.1.2 Family dynamics	2
1.1.2.1 Parentification	3
1.1.3 Caregiver Burden	3
1.1.4 Needs	4
1.1.4.1 Informational needs	5
1.1.4.2 Social needs	6
1.1.4.3 Barriers to needs	7
1.1.5 Stress and Distress	7
1.2 Theoretical framework	9
1.2.1 Resource theory	9
1.2.2 Ecological systems theory	10
1.2.3 Symbolic interactionism	10

1.3 Thesis aims	11
1.3.1 Epistemology and reflexivity	12
1.4 Thesis questions	14
Chapter Two – The unmet psychosocial and supportive care needs of young adults who have a parent with a non-communicable disease, cancer, or psychological problem: A comparative systematic review	17
2.1 Chapter overview	17
2.1.1 Review questions	18
2.2 Background	19
2.2.1 Systematic reviews	19
2.2.2 Narrative synthesis	19
2.3 Method	20
2.3.1 Inclusion criteria	20
2.3.1.1 Study population	20
2.3.1.2 Study design	21
2.3.1.3 Language of publication	21
2.4 Literature Searching	22

2.4.1 Study location	22
2.4.2 Recording of papers and de-duplication of records	22
2.4.3 Relevance screening and inclusion assessment	22
2.4.4 Included studies	25
2.5 Procedure for data extraction, quality assessment and synthesis	25
2.5.1 Data extraction	25
2.5.2 Quality assessment	26
2.6 Results and discussion	27
2.6.1 Overview	39
2.6.2 Microsystem	41
2.6.2.1 Role of the family in meeting unmet informational needs	41
2.6.2.2 Role of the family in meeting unmet supportive care needs	42
2.6.3 Detached Microsystem	42
2.6.3.1 Role of the school and peers in meeting unmet informational needs	42
2.6.3.2 Role of the school and peers in meeting unmet informational needs	43

2.6.4 Informed Mesosystem	44
2.6.4.1 Role of clinicians in meeting unmet informational needs	44
2.6.4.2 Role of clinicians in meeting unmet supportive care needs	45
2.7 Implications for counselling psychologists	45
2.8 Critique	46
2.9 Future research	47
2.10 Conclusion	48
Chapter Three – The unmet psychosocial and supportive care needs of young adults who have a parent with a non-communicable disease: An interpretative phenomenological study	49
3.1 Introduction	49
3.1.1 Background	49
3.1.2 Gender differences	49
3.1.2.1 Gender differences and the caring role	50
3.1.2.2 Gender differences and emotional defences	51
3.1.3 Family	52
3.2 Research Question	53

3.3 Methodology	54
3.3.1 Design	54
3.3.2 Participants	54
3.3.3 Materials	56
3.3.4 Procedure	57
3.3.5 Analysis	57
3.4 Results	59
3.4.1 Need for information	60
3.4.1.1 The availability of honest adult information	61
3.4.1.2 Information and emotional response	63
3.4.1.3 Desired information	65
3.4.1.4 Medicalised information as a means to normalise	67
3.4.1.5 Medicalised information for future control	68
3.4.2 The need for acknowledgment	69
3.4.2.1 The secret carer	69
3.4.2.2 Ignored carer	72

3.4.2.3 Credited carer	74
3.4.3 Support needs	75
3.4.3.1 Compassionate support	76
3.4.3.2 Required assistance	77
3.4.3.3 Family, friends and recreation	78
3.4.3.4 Social understanding	80
3.4.4 Need to be them-self	81
3.4.4.1 Introspection and escapism	82
3.4.4.2 Internalised pressure	84
3.4.4.3 Emotional impact	85
3.4.4.4 Illness cycle	87
3.4.4.5 Roles	88
3.4.4.6 Protector of others	90
3.4.4.7 Duties	91
3.4.4.8 Unacknowledged coping through practical diversions	91
3.5 Discussion	94

3.5.1 Overview of findings	94
3.5.2 Need for information	94
3.5.3 Social need	96
3.5.3.1 Social acknowledgment	96
3.5.3.2 Attachment through social development	97
3.5.3.3 Social identity and the need to be them-self	98
3.5.3.4 Family dynamics and trust	98
3.5.4 Gender differences	99
3.5.4.1 Gender differences and care giving roles	99
3.5.4.2 Gender differences and future fears	100
3.5.5 Inter-relating themes	100
3.5.6 Positive aspects	104
3.6 Chapter critique and evaluation	104
3.7 Implications for counselling psychology practice	105
3.8 Conclusion	106
Chapter Four – Young adults who have a parent with a non-communicable disease: The relationship between unmet psychosocial	107

and supportive care needs, quality of life, anxiety, depression, and stress

4.1 Introduction	107
4.1.1 Background	107
4.1.2 The value of qualitative research	108
4.1.3 Study question, aims, and hypotheses	108
4.1.3.1 Development of the OCNI and OCINI revision	110
4.2 Method	112
4.2.1 Study design	112
4.2.2 Participants	112
4.2.2.1 Sample size calculations	112
4.2.2.2 Participant inclusion and exclusion criteria	113
4.2.2.3 Procedure of participant recruitment	113
4.2.2.4 Participant numbers and return rates	114
4.2.3 Measures	115
4.2.3.1 Offspring chronic illness needs instrument (OCINI; derived from the offspring cancer needs instrument (OCNI)	115

Patterson, Pearce, & Slawitschka, 2010)	
4.2.3.2 Depression, anxiety, and stress scale (21 item short version) (DASS-21; Henry & Crawford, 2005)	115
4.2.3.3 Adult-carers quality of life scale (AC-QoL; Elwick, Joseph, Becker & Becker, 2010)	116
4.2.3.4 Demographics	116
4.2.4 Data analysis	117
4.3 Findings	121
4.3.1 Hypothesis one	121
4.3.2 Hypothesis two	129
4.3.3 Hypothesis three	131
4.3.3.1 Depression regression	131
4.3.3.2 Anxiety regression	134
4.3.3.3 Stress regression	137
4.3.3.4 Quality of life regression	140
4.4 Discussion	144
4.4.1 Hypothesis one	144

4.4.2 Hypothesis two	147
4.4.3 Hypothesis three	148
4.4.3.1 Stress	148
4.4.3.2 Anxiety	150
4.4.3.3 Depression	151
4.4.3.4 Quality of Life	152
4.5 Critique	153
4.6 Implications to counselling psychology practice	154
4.7 Conclusion	155
Chapter Five – Thesis Conclusion	157
5.1 Background	157
5.1.1 Current literature	157
5.1.2 IPA Study	158
5.1.3 Quantitative Study	159
5.2 Synergised Findings	160
5.3 Theoretical framework	166

5.4 Implications for Counselling Psychology practice	170
5.5 Thesis critique and evaluation	172
5.6 Recommendations for future research	174
5.7 Conclusion	176
Chapter Six – Critical appraisal of the research process	177
6.1 Introduction	177
6.1.1 Background	177
6.1.2 Practice experience leading to the research idea	178
6.2 What?	180
6.3 So what?	182
6.3.1 Systematic review	182
6.3.2 IPA	182
6.3.3 Quantitative	187
6.4 Implications for Counselling Psychology practice	187
6.5 Where would I take the study next?	188
6.6 How well did I meet my thesis' aims?	189

Acknowledgments

I would like to acknowledge all of the help and support that my supervisors, Dr. Wendy Nicholls and Dr. Nick Hulbert Williams gave me throughout my research from conception to submission. Their knowledge and patience has kept me going through challenging times. I would also like to acknowledge the participants who so kindly gave me their time, and Dr. Patterson's team who kindly let me adapt and use their newly created questionnaire.

Many thanks to you all.

CHAPTER ONE
LITERATURE REVIEW, THEORETICAL FRAMEWORK,
AND THESIS OVERVIEW

1.1 INTRODUCTION

Non-communicable diseases (NCDs) can be defined as a type of disease, or medical condition, which is non-infectious and cannot be transmitted between individuals. These can be of long duration and slow progress. NCDs can vary in cause, physical severity and psychological consequence (Llewelyn, Aun Ang, Lewis & Al-Abdullah, 2009). For the purpose of this thesis, the term NCD will not include cancer due to cancer being considered a life threatening and life limiting illness within society (Press, Fishman, & Koenig, 2000) in comparison to other NCDs (Llewelyn, *et al.*, 2009).

Non-Communicable Diseases (NCDs) are impacting upon the health of the global population. In 2005 there were 35 million deaths due to NCDs, of which half were in those under 70 years of age (World Health Organisation [WHO], 2011), with the chances of diagnosis increasing with older age (Office for National Statistics, 2004). The younger the patient with a NCD, the more likely it is that they'll have families and children, increasing the social impact of the illness. The WHO (2011) estimates that by 2030 deaths due to NCD will reach 52 million per year.

Currently, eighteen percent of the UK population are reported to have a NCD which affects their daily lives.

The advancement of medical interventions affords ill individuals better management options to control their illness and symptoms away from the clinical environment, and it is usual for

patients who are clinically stable to recuperate at home (Corbin & Strauss, 1988). They may require support provided by formal or informal carers such as their friends or family, with family caregivers being most frequently used (Houts, Nezu, Maguth & Bucher, 1996; Keating & Fast, 1997), possibly due to monetary issues, convenience, or a sense of family duty. The amount of caregiver input required by the ill individual can depend upon the type of illness and the biopsychosocial impact of the condition upon their daily functioning (Emanuel, Fairclough, Slutsman, & Emanuel, 2000).

In the UK there are approximately 10.8 million young adults, defined as those between 16 and 24 years of age (UK Census, 2007). An estimated 290,000 of these are carers, with 13,000 caring for another person for approximately 50 hours each week (Dearden & Becker, 2003). It is suggested that 23% of children less than 16 years of age live in a family where one member has a chronic illness or psychological problem (Dearden & Becker, 2003).

1.1.2 Family Dynamics

Parental illness can change familial roles and dynamics as the ill individual may not be well enough to fulfil daily duties, thus impacting upon routines, with family members being required to take on additional tasks. Even young children may have to undertake an unexpected and implicit caring role for their parent or siblings (Dearden & Becker, 2003). When children perform adult roles, by taking on the responsibility of care for themselves, other people and household tasks, they can become parentified (Bauman, *et al.*, 2006). The additional responsibility may overburden them and reduce their opportunity of partaking in childhood activities (Siegel & Silverstein, 2001), impacting upon their psychosocial development (Bowlby, 1969).

Adolescence is an important time for an individual's psychosocial and emotional development (Erikson, 1968) as the individual undergoes many different physical and hormonal changes. Cognitive advances afford the individual increased knowledge, abstract thinking and the ability to reason (Vygotsky, 1978). Adolescents gain differing social roles, through becoming employed or entering a romantic relationship, this gives rise to changes within the family dynamics. Identity formation is a critical developmental time for young adults (Erikson, 1968); this may be difficult for a young adult to achieve during parental illness. The family illness experience could increase the adolescent's time at home and with the family, during the adolescent developmental stage of re-identification and family detachment. This is where identity is formed through attachment processes and behaviours with peers (Erikson, 1968).

1.1.2.1 Parentification

Parentification can be conceptualised as a role reversal where the child becomes the parent to the parent. Bauman, Phuong, Silver and Berman (2001) found that daughters are more likely to become their parent's confidantes and provide them with emotional support, increasing their likelihood of depression. It could be suggested that the change in circumstances and available resources would affect the psychosocial functioning, emotional regulation, coping and adjustment of the family unit.

1.1.3 Caregiver Burden

Caregiver burden is a biopsychosocial response to caring which occurs in informal and formal carers when emotional and physiological health resources are depleted (Given *et al*, 1992). Caregiver burden can affect individuals in a plethora of ways. They can experience interpersonal communication issues (Morris, Morris & Britton, 1988; Savundranayagam, Montgomery &

Kosloski, 2011), embarrassment, resentment and isolation from society (Kelly, 2010; Zarit, Reever & Bach-Peterson, 1980). It could be argued that adolescents would have additional burden in adjusting to the illness situation which threatens their sense of family safety and security.

Research with informal and formal adult caregivers suggest that burden is associated with the individual's experience of unmet needs, and that affects the caregiver's ability to help the ill individual (Schubert, Kinzie & Farace, 2008; Sharpe, Butow, Smith, McConnell & Clarke, 2005). This association could be due to the ill individual feeling that they do not have the required resources to meet their changing needs, increasing feelings of vulnerability. In an attempt to regain control and self-efficacy, the ill individual may focus upon unrealistic targets as the solution to their ill health. The carer could feel as though they are unable to meet demands and are ineffective in their job, thus impacting upon their confidence.

1.1.4 Needs

Needs are the requirement of some necessary, desired, and useful action or resource which helps attain optimal well-being (Foot, 1996). Maslow (1943) theorised the hierarchy of needs which are sequentially ordered (Physiological, Safety, Love/Belonging, Esteem, Self Actualisation) in accordance to their importance for survival and motivation. These needs are generalised for motivation and have been used within social sciences and occupational psychology, yet have not been widely related to health related needs. Zalenski and Raspa (2006) applied Maslow's (1943) model to an illness framework (distressing symptoms; fears for physical safety and/or abandonment; affection, love and acceptance in the face of illness; esteem, respect, and appreciation; self-actualisation and transcendence), to help inform needs-based interventions.

Sharpe, *et al.*, (2005) found that the ill individual's unmet needs are associated with caregiver burden and that carers were more able to identify needs than the ill individual. Sharpe *et al.*'s (2005) research, however, had a large number of elderly 'patient' participants who are less likely to report unmet needs (Sanson-Fisher, *et al.*, 2000) possibly due to their desire to retain some independence (Nijboer, *et al.*, 1999). When clinicians conduct patient assessments they generally ask ill individuals about their needs and any additional support they require. If the ill individual does not recognise required resources, either due to their lack of awareness or to carers protecting them from extraneous stress, it could limit the family's and caregivers' access to psychosocial and supportive care services which may aide the patient and carers.

1.1.4.1 *Informational needs*

Information is important in helping families adjust to a diagnosis of ill health (Auerbach, Martelli, & Mercuri, 1983; Hymovich, 1995). Research with individuals with breast cancer and their spouses has demonstrated that information needs are increased in ill individuals who are young, have a high educational level and a shorter time since diagnosis; level of education was the only predictive factor for spouses (Salminen, Vire, Poussa, & Knifund, 2004), indicating that information need is moderated by the young adult's educational level and maturity.

Having informational needs met has been identified as essential in reducing distress in ill individuals, their spouses and both formal and informal caregivers (Abrahamson, Durham & Fox, 2010; Moser, Dracup & Marsden, 1992). Gursky (2007) suggests that children who have a sibling in hospital and received adequate, age-specific information manage their coping strategies more adaptively than siblings who had less adequate information. It could be argued

that receiving information could increase feelings of family cohesion and security, thus reducing the taboo surrounding difficult discussions about the illness (Roloff & Ifert, 2000).

1.1.4.2 *Social needs*

Spouses, formal and informal caregivers have varying psychosocial and supportive care needs. They need contact with clinicians, emotional support, confidential talk, and time-out away from the illness experience where they can re-identify with society (Moser *et al.*, 1992; Soothill, *et al.*, 2001). Having contact with clinicians would likely increase the clinician's ability to implement more support, as Sharpe *et al* (2005) suggests caregivers are more aware of the unmet psychosocial and supportive care needs of the ill individual than the 'patient'. By having contact with clinicians, caregivers would gain access to required resources, feel as though they were a valued member of the caring team, and able to receive adequate information to fulfil their role. Social support can help increase an individual's adaptive emotional coping (Hilton & Elfert, 1996); it also opens up access to information. Northouse and Swain (1987) suggest that having access to, and communication with, individuals who have shared experiences can be more important than the sharing of information. This contact potentially normalises the situation and subsequent emotional and psychological impact, which in turn, could act as a form of emotional release and debriefing.

1.1.4.3 *Barriers to needs*

Needs can be enduring due to social barriers impeding access to supportive care either due to lack of information, accessibility, or social stigma; the latter is more likely for individuals who have a psychological rather than physical health problem (Corrigan, 2005). Information is more

available to individuals as their age increases, as they have more freedom and comfort in accessing web based information which they can tailor to meet their own informational needs (Dina, Borzekowski & Vaughn, 2001) thus increasing avenues of resources. Young adults who have a parent with a NCD may have increased unmet needs due to their limited social power, being their ability to influence the behaviour of others in getting their needs met through increased recognition in society. Their lack of power limits their ability to gain access to resources which could ameliorate some need. Their level of caring experience, immature friendship groups (Williams & McGillicuddy De-Lisi, 2000) and disruption of family life, dynamics and roles also impact upon their need for additional resources (DiMatteo, 2004; Garmezy, 1991).

1.1.5 Stress and Distress

Stress has typically been conceptualised as a state which occurs when demands outstrip coping resources (Lazarus & Folkman, 1984). Distress in adult carers increases in-line with the caring duration and transitions into and out of the caring role (Burton, Zdaniuk, Schulz, Jackson, & Hirsch, 2003; Hirst, 2005). It could be assumed that young adults who have a parent with a NCD would experience stress and distress due to their changing family circumstances, being conceptualised as a threatening situation, resulting in a loss of routine and normalcy (Hobfoll & Lilly, 1993), potentially increasing their risk of psychosocial hardship. Hardiness is suggested to have a moderating effect on the stress and distress processes through reliance upon adaptive psychological and behavioural coping, such as the use of social support and intrapersonal reflective practices (Maddi, 2006). Adolescent children may not have access to mature, intimate and loyal friendship groups (Pendley, et al., 2002), support and knowledge (Foucault, 1988) or

have developed adaptive intrapersonal coping strategies or mechanisms. The lack of resources and enduring illness could therefore be hypothesised to impact upon the individual's ability to cope with the changing situation.

The literature within this chapter has thus far demonstrated that unmet needs have mainly been examined with formal and informal adult carers of cancer patients, and that unmet needs are associated with negative effect. Adolescents have more barriers in accessing resources, increasing the endurance of unmet needs, thus impacting upon their distress and coping behaviours, as loss and the subsequent need of resources are associated with increased distress and decreased coping. This thesis argues that the unmet psychosocial and supportive care needs in adolescent children who have a parent with a NCD is an important area of investigation, owing to NCDs becoming more prevalent within society and likely to affect the family system.

1.2 THEORETICAL FRAMEWORK

This thesis' theoretical framework is a collection of interlinking concepts to help guide and inform the research efforts and analysis. The broader framework of the included models and theories may offer new insight into provision for needs-based interventions.

1.2.1 Resource Theory

Conservation of resources (COR) theory (Hobfoll 1989; 1998) assumes that stress can occur when people experience loss of resources, when resources are threatened, or when people invest their resources without subsequent gain. Hobfoll and Lilly (1993) found that only loss of resource was associated with distress, yet this contravenes the assumptions held within the critical life events approach. This approach suggests that stress occurs when an individual is

required to adjust to either positive or negative changes in their circumstances (Holmes & Rahe, 1967).

Resources can be categorised as *object resources*, being physical objects such as the home or access to transportation, *condition resources* such as employment and personal relationships, *personal resources* such as skills or self-efficacy, and *energy resources* being the ability to obtain other resources, such as money or knowledge (Hobfoll, 1989). Resource theories of stress are concerned with sources which preserve well-being in the face of stressful encounters.

Interpersonal relations, such as social support (Schwarzer & Leppin, 1991), and intrapersonal factors, such as hardiness (Kobasa, 1979), optimism (Scheier & Carver, 1992), and self efficacy (Bandura, 1977), can help moderate the effects of the stress.

1.2.2 Ecological Systems Theory

Ecological systems theory (Bronfenbrenner, 1979) is similar to the gestalt construct which suggests that the whole is greater than the sum of its parts. The family is a microsystem, and illness within that system will likely affect interpersonal dynamics and interactions (Bowen, 1976). Members of the family also have unique and independent links, being the mesosystem, within the immediate wider society (i.e schools), and these systems inter-relate within the wider cultural and political macrosystem (Bronfenbrenner, 1979). The family unit, although independent, is influenced by friends, neighbours, colleagues, peers, and government policy; these could all influence the individual's evaluation of an illness experience and access to support, as each member will have different relationships between contexts.

1.2.3 Symbolic Interactionism

Symbolic interactionism (Blumer, 1969) posits that individuals respond to the social understanding of reality as opposed to 'true' reality. It is hypothesised that individuals exist in three different realities being 1) objective/physical reality, 2) social reality, and 3) unique reality, being the individual's interpretation of reality through the introjections of other people. Individuals and society are interconnected and cannot be independently understood as they are constructed through social interaction.

Systems theory and symbolic interactionism are two theoretical frameworks which are closely inter-related and are likely to influence family coping and illness adjustment (Chalmers, et al., 2000; Kristjanson, Chalmers & Woodgate, 2004). When these are joined with the conservation of resource theory they form a larger theoretical framework on how individuals and society interact and appraise situations which could influence their need of psychosocial and supportive care resources and the ability for them to be obtained.

1.3 THESIS AIMS

To date there is little research which investigates young adult's conceptualisation of their unmet psychosocial and supportive care needs when they have a parent with a NCD. It is likely that adolescent children are at risk of distress and maladaptive coping during the illness experience, and that appropriate and tailored, needs-based interventions will help with current and future psychosocial coping (Watson, *et al*, 2012). Research suggests that parental reports can downplay the emotional effects of their illness upon their child (Lewis, Ellison & Woods 1985; Lewis, Hammond & Woods, 1993; Welch, Wadsworth & Compas, 1996). This could be due to their not wanting to face the consequences of their condition, or due to the child protecting their parent from any stress or pain by not wanting to externalise any felt effects. Nicholson, Biebel, Hinden,

Henry and Stier (2001) suggest that the young adult's phenomenological experience is essential to help determine their requirements in the hope of alleviating distress.

Deductive methods of assessing young adults' needs is comparable to the expert driven approach of needs assessments conducted by health care professionals on their patients (Boberg, Gustafson, Hawkins, Offord, Koch, Wen, *et al.*, 2003; Lehr & Strosberg, 1991). The 'top down' method of professional power and expert opinion differs to the counselling psychologist's philosophy of client as expert (Woolfe, Strawbridge & Dryden, 2009), which is essential in discovering the phenomenological experience and subsequent needs of adolescent children (Palmer, Wilson-Smith & Hulbert-Williams, *under review*). This thesis will pragmatically investigate adolescent children's experiences, conceptualisations, and biopsychosocial effects of their unmet psychosocial and supportive care needs when they have a parent with a NCD.

1.3.1 Epistemology and Reflexivity

Reflexivity must be noted as any research findings will reflect aspects of the researcher. This thesis is being written as part of the requirement for fulfilling the practitioner doctorate in counselling psychology, by a practitioner who works within physical health. As such, the researcher's underlying knowledge, practice and philosophical beliefs will influence the choice and narrowing of research question, implications and recommendations to practice and further research.

Epistemology is linked with ontology inasmuch as there are different ways of viewing, conceptualising and validating reality. Counselling psychologists have an interest in the expert opinion of their clients and as such may use interpretative phenomenological analysis (IPA) to explore and analyse data. IPA has a theoretical basis of hermeneutics (Palmer, 1969),

phenomenology (Moran, 2000) and ideography (Smith et al, 1995) and interlinks the subjective experience of participants with symbolic interactionism (Blumer, 1969). The aim of IPA is for the researcher to interpret how individuals make sense of their world and place within society.

Mixed methodology has gained increasing popularity in spite of the paradigm debate (Reichardt & Rallis, 1994) which questions the effectiveness of mixing and subsequent fitting together of qualitative and quantitative methodologies (Smith, 1983); yet the research methodology must be informed by the research question. Pragmatism values a 'what works' approach through valuing both subjective and objective knowledge (Cherryholmes, 1992).

The pragmatic approach to research seeks to transcend the division between context-dependent qualitative and universal and generalisable quantitative research to determine if findings can be transferable.

Whilst the research question should always guide the route of methodology, there are certain forms of research which are held in higher esteem than others. Within a medical/physical health setting, there has been increased admiration for qualitative research, yet the preferred and most revered methodological paradigms are those which are quantitative. This is possibly unsurprising due to medical setting generally having to work to statistics and numerical data (i.e. hemodynamic and bio-chemical markers). In order for this research to have a greater impact upon medical settings, it was felt that being able to back up qualitative data with more widely accepted and understood analysis would be beneficial in getting the research recommendations implemented within the medical setting.

This thesis will use a pragmatic paradigm to gain a holistic perspective in examining the thesis questions. The findings of this thesis will go towards informing needs-based interventions which

would be beneficial to counselling psychology practice as it is suggested that needs assessments help improve an individual's coping and adjustment processes. The implementation of service provider needs-based interventions will help ameliorate current and future distress (Watson, *et al.*, 2012).

1.4 THESIS QUESTIONS

In order to investigate the unmet psychosocial and supportive care needs of young adults who have a parent with a NCD, the following questions will be asked and examined using appropriate mixed methodology paradigms.

A systematic review will contextualise current knowledge surrounding the unmet psychosocial and supportive care needs of adolescents who have a parent with a NCD, and see if literature on unmet needs in other conditions can offer additional insight. The findings of this will help direct the empirical arm of this thesis, which has two different follow on questions: (i) a qualitative investigation of adolescent's experiences and conceptualisations of unmet needs when they have a parent with a NCD; (ii) a quantitative investigation looking at association of unmet needs upon affect and well-being.

Question 1: a) What do we already know from the literature about the unmet psychosocial and supportive care needs of adolescents when they have a parent with a NCD, and b) what can be learned from the cancer and psychological health literature?

The initial findings of questions one and two will be derived from information which is grounded within the literature; this will inform the thesis' investigative direction. These questions will be examined by conducting a systematic review to summarise all relevant findings of included

individual papers. Published literature will be investigated and synthesised in a coherent way in order to determine adolescent children's unmet psychosocial and supportive care needs. The results will make reference to the theoretical framework of systems theory, COR and symbolic interactionism. The review will highlight any gaps in the literature, thus helping to inform further research.

Question 2: What are the experiences and conceptualisations of unmet psychosocial and supportive care needs of young adults who have a parent with a NCD?

The adolescent child's phenomenological experience of their psychosocial and supportive care needs will be examined using qualitative methodology in order to make meaning and sense of the adolescent child's own subjective experience (Willig, 2001). Semi-structured interviews will be constructed using questions based broadly upon the findings which emerge from questions one and two. Interpretative phenomenological analysis is well suited to investigating health related topics where there is a need for increased information about individuals' understanding and perception of their experiences (Smith & Eatough, 2007). These findings will be used to test the appropriateness of the Offspring Cancer Needs Inventory (OCNI; Patterson, Pearce & Slawitschka, 2010) within adolescents who have a parent with a NCD.

Question 3: What is the relationship between adolescent children's unmet psychosocial and supportive care needs, quality of life, anxiety, depression, and stress scores?

This thesis has been given permission to use a newly developed questionnaire from the Australian Canteen Organisation. The Offspring Cancer Needs Inventory (OCNI; Patterson, *et al.*, 2010) has been piloted with adolescent children who have a parent with cancer to determine frequency and types of need. The questionnaire study of this thesis will quantitatively examine

the association of unmet psychosocial and supportive care needs, affective state and quality of life outcome measures of adolescent children who have a parent with NCD. Question three examines participants unmet needs by using the OCNI to a) determine types and most frequent adolescent child unmet psychosocial and supportive care need, and b) investigate the association and predictive power of unmet needs with affective state and quality of life.

CHAPTER TWO

ABSTRACT

This comparative systematic review analyses published literature on unmet psychosocial and supportive care needs of young adults who have a parent with a chronic illness, cancer, or a psychological problem. For this review a comprehensive systematic search was completed, and of the 1479 papers extracted seven were included, of these five papers related to cancer, one to non-communicable disease (NCD) and one psychological problems. Owing to the disparity in number of papers between types of illness, comparisons were difficult to make. Analysis suggests that adolescent children who have an ill parent have informational, emotional, practical and social support needs.

Further research investigating adolescent children's conceptualisations and experiences of unmet needs when they have a parent with a NCD is needed; this could inform further supportive interventions, and offer the family holistic care. It is suggested that such research would be well suited to be investigated by counselling psychologists due to counselling psychology's humanistic philosophy of valuing the client experience. Findings would help inform needs-based interventions which would help relieve current and future distress.

KEYWORDS: unmet needs, non-communicable disease, cancer, psychological problems, adolescent children, systematic review.

CHAPTER TWO
THE UNMET PSYCHOSOCIAL AND SUPPORTIVE CARE NEEDS OF
YOUNG ADULTS WHO HAVE A PARENT WITH A
NON-COMMUNICABLE DISEASE, CANCER OR PSYCHOLOGICAL
PROBLEM:
A COMPARATIVE SYSTEMATIC REVIEW

2.1 CHAPTER OVERVIEW

The narrative theoretical literature review and thesis aims in Chapter One demonstrated that young adults who have an ill parent will likely have different needs to adult caregivers, and require different types of access to resources and social support. To establish what is already known on this topic, this study will present a systematic review of the published literature on unmet psychosocial and supportive care needs of young adults who have an ill parent. The findings will ensure that a thorough and robust literature review informs the direction of the research within this thesis.

Appropriate access to required resources and support has been demonstrated to improve coping and reduce distress (Aldwin, 2009; Morosso, Capelli & Viterbori, 1999). Family changes during the illness experience (Bowen, 1976) will likely impact upon adolescent children, creating different needs to adults and spouses due to their ability to access social support (Foucault, 1988; Pendley, et al., 2002) and to harness their current knowledge. Needs may focus on regaining ‘normal’ family life by restoring that which has been lost or changed during the parental illness, as this can be a cause of increased stress (Hobfoll & Lilly, 1993). External resources, which could help fulfil needs and

ameliorate psychological and emotional discomfort, are derived through interactions within the individual's existing social systems. These have the ability to influence individual's illness experiences, appraisals (Blumer, 1969) and accessible resources, thus moderating their stress process (Bandura, 1977; Schwarzer & Leppin, 1991).

On initial literature screening it became apparent that research surrounding the unmet psychosocial and supportive care needs of young adults who had an ill parent from the adolescent child's view point was sparse. Literature examining the psychological and emotional effects of unmet needs in formal and informal adult caregivers and family members has mainly been studied within the cancer literature; this study will also attempt to locate those studies investigating needs of children of parents with NCDs and psychological conditions. The findings from this study will be conceptualised within the theoretical framework of ecological systems theory (Bronfenbrenner, 1979), conservation of resource (COR) theory (Hobfoll, 1989) and symbolic interactionism (Blumer, 1969).

2.1.1 Review Questions

This review will synthesise published literature on young adult's unmet psychosocial and supportive care needs across parental cancer, psychological problems and NCD. The systematic process will ensure inclusion of all relevant papers into the synthesis. To date no systematic review has investigated the unmet psychosocial and supportive care needs of young adults who have a parent with a NDC. This review will ask two primary questions.

1) What do we already know from the literature about the unmet psychosocial and supportive care needs of adolescents when they have a parent with a NCD, and what can be learned from the cancer and psychological health literature?

The review protocol was written following guidance set out by the NHS Centre for Reviews and Dissemination (NHS CRD; Khan, Reit, Glanville, Sowden & Kleinjnen, 2001), the Cochrane Collaboration (Higgins & Green, 2005), and Petticrew and Roberts (2006).

2.2 BACKGROUND

2.2.1 Systematic Reviews

Traditional literature reviews can be subject to bias due to the researcher's selection and interpretation of included papers. Systematic reviews endeavour to produce a replicable review through an objective and scientific approach to the literature process (Egger, Smith & Altman, 2001). Papers are identified from systematic and standardised search strings and pre-defined inclusion methodologies. To further reduce bias, the selection of papers is determined by double screening by two researchers, and included studies are then systematically critiqued in order to determine the validity of their contribution.

2.2.2 Narrative Synthesis

Narrative literature synthesis attempts to draw out and integrate findings across studies as its key feature is its textual approach in telling each study's story (Petticrew & Roberts, 2006). It can also involve the manipulation of statistical data where papers also

have some quantitative analysis. Narrative synthesis has been chosen as the method of data combination as it is a beneficial approach of analysis for synthesising qualitative research investigating individual's phenomenological experience in an under-researched area (Dixon-Woods, Agarwal, Jones, Young & Sutton, 2005). The Cochrane Collaboration (2001) suggests that narrative synthesis is not the gold standard of data synthesis as they can still be prone to some of the biases of a non-systematic review. But they do have a purpose as they are used to inform evidence based empirical hypotheses; early stage research which utilised narrative synthesis has an increased chance of the scientific study being used in policy (CRD, 2009).

2.3 METHOD

2.3.1 Inclusion Criteria

Inclusion criteria are essential in ensuring that bias is minimized during the selection of included papers. It gives a standardised procedure, which both the author and the second reviewer (here, the research supervisor) can adhere to and follow.

2.3.1.1 Study population

The review was concerned with the unmet psychosocial and supportive care needs of adolescent children who have a parent with a NCD, cancer or psychological problem. Adolescents were the target population. Where studies included children with a variety of ages, papers were included, provided the majority of the sample was classified as 'youth', being aged between 10 and 24 years (WHO, 2011). This review was concerned with the adolescent children's own experiential understanding of the illness event and

their needs. Papers which contain the opinions and experiences of proxy informants (i.e. parents, clinicians, ill individuals) and the young adults were included, but only the young adult's experiences was extracted and synthesised. Papers where opinions could not be reliably related back to the adolescent child were excluded.

It was suggested that individuals who have a genetic connection to an ill individual may have increased consideration for their own well-being, due to literature and educational material citing the genetic heritability of illnesses (i.e. familiar cancer, schizophrenia, irritable bowel syndrome). Therefore the adolescent's biological parent must have been diagnosed as having a NCD, cancer or psychological problem. It was assumed that if not otherwise stated the papers were looking at biological, as opposed to adopted or fostered, family members.

2.3.1.2 *Study design*

The review was designed to locate all relevant published literature on adolescent children's unmet psychosocial and supportive care needs, and for this reason both qualitative and quantitative papers were included. Dixon-Woods, *et al.*, (2005) suggest that it is important to integrate qualitative and quantitative data in systematic reviews in order to gain a robust overview of current knowledge. Excluded papers comprised of literatures reviews, books, book reviews, and dissertations.

2.3.1.3 *Language of publication*

Whilst papers produced in languages other than English may have given increased insight, due to the limited resources available to the author, papers published in a foreign language were excluded. Foreign language assistance would have been required at all stages of relevance screening, inclusion and quality assessment, data extraction and synthesis, and this was unfortunately not feasible.

2.4 LITERATURE SEARCHING

2.4.1 Study Location

Electronic searches were carried out between September 2010 and November 2011. To the authors knowledge no studies have been since published within leading journals which would invalidate the findings held within this review.

2.4.2 Recording of Papers and De-Duplication of Records

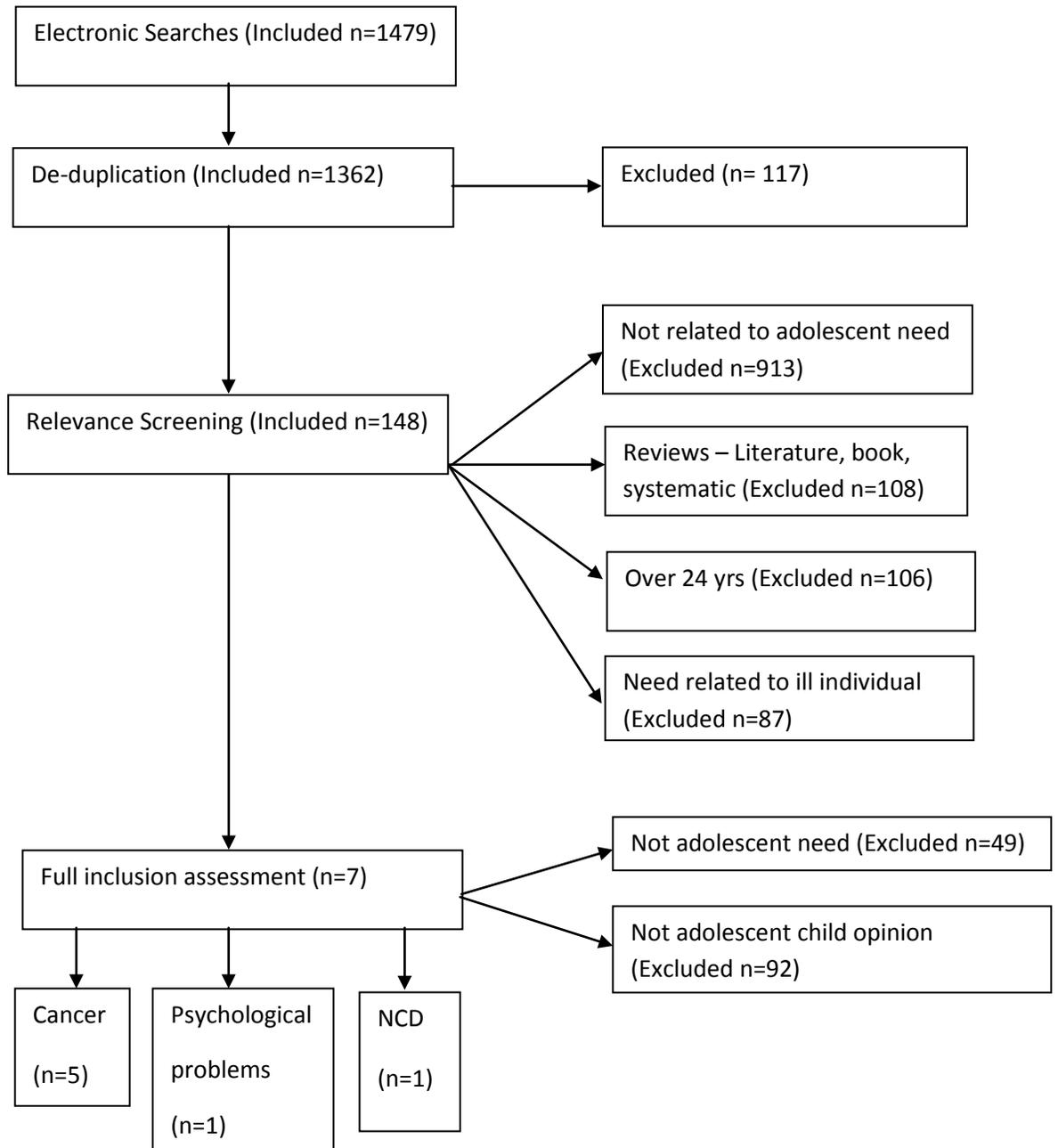
Electronic searches, using a search string (appendix 2.1) were conducted on Medline, PsycINFO, Ahmed, Embase and CINAHL databases; these were imported into EndNote journal database program. Included articles had their reference lists screened for any additional articles in order to ensure that all relevant papers were captured; these were manually inputted into the database. References were de-duplicated by manual methods and using EndNote functions.

2.4.3 Relevance Screening and Inclusion Assessment

Articles were identified and included in three stages. The database of all de-duplicated papers was screened for relevance by the author and research supervisor. First, each title

was screened to decide upon eligibility. Second, all eligible titles had their abstracts read to determine if they met the inclusion criteria. Thirdly, each paper was independently read to determine final inclusion into the review. It was agreed that where both author and research supervisor disagreed upon the validity of a paper's inclusion it was debated; this situation did not arise. Figure 2.1 presents a flow chart showing the narrowing of the literature search through de-duplication and relevance screening.

Fig 2.1 Flow chart showing the narrowing of the literature search through de-duplication and relevance screening



2.4.4 Inclusion Studies

Seven articles (six qualitative and one mixed methodology) were identified for full inclusion assessment. There was a notable difference in the number of papers between cancer, NCD, and psychological problems, with more cancer papers being identified. The increased amount of papers in the cancer category is likely a testament to the amount of funding and special interest groups within psycho-oncology. Of the seven included articles, there were two occurrences where two qualitative publications used the same participant data within the literature of the cancer subtype. The findings of these qualitative papers were independently included within the review, yet the participant numbers were only accounted for once.

2.5 PROCEDURE FOR DATA EXTRACTION, QUALITY ASSESSMENT AND SYNTHESIS

2.5.1 Data Extraction

Data extraction from all included studies was completed by the author; whilst it would have been beneficial for another researcher to have completed a duplicate extraction of data; due to resources this was not feasible. Data extraction included recording the *Basic Study Information* such as author details, date, overview of the study and allocation of study identifying marker; *Sample information* including sample size, age, gender, and type of ‘illness’; *Methodology* being the mode of analysis, and *Results* detailing the findings which were relative to the adolescent’s conceptualisation of unmet psychosocial and supportive care needs in relation to parental ‘illness’.

2.5.2 *Quality Assessment*

The Critical Appraisal Skills Programme (CASP; National Collaborating Centre for Methods and Tools, 2006) developed by Solutions for Public Health at the Public Health Resource Unit was used by the researcher to critically appraise the studies held within this review. The CASP (2006) identifies ten questions which look at rationale, aims, methodology, reflexivity, ethical issues, analysis, and findings. It was predetermined by the researcher that any paper which received a score below seven was excluded from the synthesis due to the standard of quality not being robust enough to contribute to the findings. The CASP (2006) found that the identified papers were all eligible to be included. Each paper's score is reported under the author column in table 2.2. Full CASP (2006) sheets for each included article are in the appendices (see appendix 2.2).

2.6 RESULTS AND DISCUSSION

Table 2.1 Summary information of the systematic search results for unmet psychosocial and supportive care needs in young adults who have a parent with cancer, NCD, or psychological problems.

ID	Author	Date	Study Details	Sample	Analysis	Main Findings	
						Adolescents Needed <i>Information Needs</i>	Adolescents Received <i>Information Received</i>
[1]	Chalmers, Kristjanson, Woodgate, Taylor-Brown, Nelson, Ramserran & Dudgeon. (CASP 8)	2000	Role of the school in providing information and support to adolescent children of women with breast cancer.	31 adolescents aged 12-20 years. [9 male, 22 female] who had a mother with breast cancer. [same	Content analysis.	- To have information about survivability and the emotional and psychosocial impact upon the family and the ill individual.	- Taught, curriculum based lessons from teachers (as opposed to school nurses). General, biomedical and statistical information on prevalence, mortality,

ID	Author	Date	Study Details	Sample	Analysis	Main Findings
[1]				sample as [5])	<p>timing and material, females requiring information on heritability of breast cancer.</p> <p><i>Supportive Care Needs</i></p> <p>- School to offer detachment from the cancer experience</p>	<p>aetiology, symptoms and prevention.</p> <p>- Untimely with relation to the adolescents experience with meaning being lost on other students.</p> <p><i>Supportive Care Received</i></p> <p>- Half of the adolescents had supportive teacher-</p>

ID	Author	Date	Study Details	Sample	Analysis	Main Findings
[1]						and normalcy. student encounters. - Recognise the situation and offer heartfelt interpersonal interactions. - School counsellors involved if students had previously attended therapy.
[2]	Handley, Farrell, Josephs, Hanke & Hazelton. (CASP 8)	2001	The needs of children with a parent with psychological problems.	4 female children, (3 were siblings) aged 11-15 years.	Thematic analysis.	<i>Information Needs</i> - Aetiology, concerns re future and parent safety, genetic heritability, honest information. <i>Supportive Care Needs</i> - Emotional support through talking to family members and teachers. - Family understanding and cohesion during

ID	Author	Date	Study Details	Sample	Analysis	Main Findings
						parental hospitalisation, individual counselling and support groups.
[3]	Kennedy & Lloyd-Williams. (CASP 8)	2009a	How children cope when a parent has advanced cancer.	11 children aged 8-18 years 2 male, 9 female. (Same sample as [4])	Grounded theory.	<p><i>Information Needs</i></p> <ul style="list-style-type: none"> - Future and family health risks. - Information to help inform certain coping strategies. - Positive information, feel good media stories. <p><i>Supportive Care Needs</i></p> <ul style="list-style-type: none"> - Support during treatment and illness side effects, especially for children who undertook a 'caring' role. - Faith. - Confidential talk with an external individual

ID	Author	Date	Study Details	Sample	Analysis	Main Findings
[3]						<p>to ameliorate family worry.</p> <ul style="list-style-type: none"> - Positive outcomes of becoming closer as a family, appreciating each other and learning how to care. <p><i>Recreational Needs</i></p> <ul style="list-style-type: none"> - Distraction, recreation and normalcy, including spending time with the ill parent and spending time with friends. <p><i>Practical Needs</i></p> <ul style="list-style-type: none"> - To have a manageable amount of responsibility. - Positive outcome of being prepared for adult life.

ID	Author	Date	Study Details	Sample	Analysis	Main Findings
[4]	Kennedy & Lloyd-Williams. (CASP 8)	2009b	Informational and communication needs of young adults.	11 children (2 male, 9 female) (same sample as [3]).	Grounded theory.	<p><i>Informational Needs</i></p> <ul style="list-style-type: none"> - Information about cancer to help prepare for the future. Individual differences influenced the amount of information the child required, some wanting total honesty, others requiring more filtered and gentle information. - Daughters wanted information regarding future tests and their chances of hereditability. - Information to start as general and factual and then be practical so children knew how to care. - Different sources. <p><i>Supportive Care Needs</i></p>

ID	Author	Date	Study Details	Sample	Analysis	Main Findings
[4]						- Communication with parents, friends, teachers, and health professionals.
[5]	Kristjanson, Chalmers & Woodgate. (CASP 8)	2004	Information and support needs of adolescent children of women with breast cancer.	31 adolescent children aged 12-18 years. (same sample as [1])	Grounded theory.	<p><i>Informational Needs</i></p> <ul style="list-style-type: none"> - Different types and sources of information at through differing means of communication at different timings. - Adolescents reported information needs being largely unmet. <p><i>Supportive Care Needs</i></p> <ul style="list-style-type: none"> - Sense of hope. - To feel included. - Peer and school support. - Emotional understanding.

ID	Author	Date	Study Details	Sample	Analysis	Main Findings
[5]						<ul style="list-style-type: none"> - Reciprocal interpersonal relationships with friends. - Communities useful to the ill individual yet not to the personal needs of the adolescent. - Adolescents reported supportive needs being largely unmet. <p><i>Need for a Sense of Self</i></p> <ul style="list-style-type: none"> - 'Normal' feelings and normal adolescent feelings. - Individualised interventions based upon family situation and adolescent needs.

ID	Author	Date	Study Details	Sample	Analysis	Main Findings
[6]	Thomas, Stainton, Jackson, Cheung, Doubtfire & Webb. (CASP 7)	2003	Unmet needs in the lives of young carers.	27 young carers, aged 9- 18 caring for a family member. 18 were caring for sick, disabled or alcoholic parent.	Computer coded analysis. Specific analysis not stated.	<p><i>Recognition Needs</i></p> <ul style="list-style-type: none"> - Failure of schools to recognise the biopsychosocial impact of caring. - The desire for acknowledgement, but without schools being over-intrusive. - Need for recognition and communication from healthcare professionals. <p><i>Recreational Needs</i></p> <ul style="list-style-type: none"> - Need for friendships, peer support and recreation. <p><i>Practical Needs</i></p> <ul style="list-style-type: none"> - Increased responsibility causing stress; additional fear at leaving the person alone.

ID	Author	Date	Study Details	Sample	Analysis	Main Findings
[6]						- Positive outcome of feeling prepared to live away from home.
[7]	Patterson, Pearce & Slawitschka. (CASP 9)	2010	Development of the Offspring Cancer Needs Instrument (OCNI)	Study 1: 14 young adolescents, aged 12-24 years. Study 2: 116 young adolescents / adults, aged 12-24 years.	Mixed methods: Study 1 Content analysis. Study 2 Scale reliability and correlation analysis	Content analysis informed questionnaire construction. Reliability scores of the newly developed OCNI were within acceptable parameters. Unmet needs were associated with depression (r=0.77, p=<.001), anxiety (r=0.66, p=<.002) and stress (r=0.56, p=<.01). Top Ten Needs (current needs) and Enduing Needs (needs which have not been met during a period of 12 months): <i>Information Needs</i> - 80.2% had a need for information.

ID	Author	Date	Study Details	Sample	Analysis	Main Findings
[7]						<ul style="list-style-type: none"> - 71.6% needed information about survival <i>Enduring Information Needs</i> - 31% information about side effects - 27.6 to meaningfully talk with a clinician. - 26.7 to speak to a clinician when needed <i>Supportive Care Needs</i> - 86.8% required understanding from friends. - 83.6% support from friends. - 75% express feelings about cancer. - 73.3% discuss feelings and fears. <i>Enduring Supportive Care Needs</i> - 44% understanding from friends. - 39.7% support concentrating at school/work.

ID	Author	Date	Study Details	Sample	Analysis	Main Findings
[7]						<ul style="list-style-type: none"> - 30.2% open communication with friends. - 28.4% support from friends. - 27.6% help with emotional regulation <p><i>Recreational Needs</i></p> <ul style="list-style-type: none"> - 81.3% have fun. - 80.2% spend more time with friends. - 73.3% spend time with others. - 71.6% participate in social activities. <p><i>Enduring Recreational Needs</i></p> <ul style="list-style-type: none"> - 29.3% a safe haven during difficult times. <p><i>Enduring Need for a Sense of Self</i></p> <ul style="list-style-type: none"> - 30.2% issues with self esteem.

Throughout this section the papers included in the review will be referred to by their unique ID which will appear in square brackets within the text.

2.6.1 Overview

This review aimed to determine: (i) the type of unmet psychosocial and supportive care needs of young adults who had a parent with cancer, NCD, or psychological problem; and (ii) if needs varied between illness types. Due to the majority of the papers being from the psycho-oncology literature, any generalisation to the wider unmet psychosocial and supportive care needs of young adults who have a parent with a NCD other than cancer, are difficult to make. Some of the articles investigated the role of the school in unmet psychosocial and supportive needs of adolescent children. These papers are likely to have placed more investigative analysis upon the role of the school as opposed to family and friends. The synthesis suggests that adolescent children who have an ill parent have a range of needs, which are in the main, unmet [5,7]. The authors of the included papers found adolescent children have needs relating to *information, practical duties, recreation, emotions, acknowledgement and recognition* through societal introjections, and the need to regain a *sense of themselves* as a ‘normal’ teenager. Quantitative analysis [7] found evidence suggesting a positive association between the number of unmet needs and negative affective state.

Informational needs were noted in all seven papers with the authors finding that information needed to be honest, yet pitched at an appropriate intellectual level and at the right time in the duration of the parental illness for the adolescent child; 80% of adolescents wanted information about the illness, and 71% wanted information about survivability [7]. The young adults requested information about how other adolescents have coped [1] thus giving them insight into

their ways of coping, and potentially making them feel less alone and part of a new peer subgroup. The findings of the included papers indicated that *practical needs* were present in three papers relating to cancer and NCDs [3,6,7], with individuals stating that they needed to have manageable amounts of responsibility in order to manage stress levels. The findings suggest that they were fearful of causing injury through their doing something wrong, and in leaving the ill individual alone, in case their parent took a turn for the worse whilst the young adult was absent. Authors reported that the practical tasks had made them feel more able to cope with adult responsibility in the future. The need for *emotional support* and *understanding* was evident in all of the papers; three-quarters of the young adults in study [7] wanted to be able to discuss cancer. Emotional need had different ways of being fulfilled, either through information or confidential talk which aided intrapersonal and interpersonal understanding and increased adaptive coping. The need for *recreation* and *timeout* with either family or friends was noted in four papers [3,5,6,7], with 81% needing to be able to have fun [7]. The authors suggested that recreation helped the adolescent child's coping through being distracted and regaining some normalcy. Both timeout and recognition was important for young adults in reconnecting to themselves as a teenager as this was defined as a need in one paper in the cancer category [5]. The need for *acknowledgement and recognition* was present in three papers investigating adolescent need in cancer and NCD [1,5,6]. Recognition and acknowledgment by family and society could reduce barriers to resources which could aid the young adult's coping by reducing stressors. The adolescent child's stress may also be reduced as acknowledgement could be considered to be a gain, thus helping to ameliorate feelings of hopelessness and stress (Hobfoll, 1989). The type of unmet psychosocial and supportive care needs and the accessibility of these needs are all highly inter-related, insomuch that social support can open up avenues of increased information,

practical and emotional support. This could indicate that meeting specific needs would be beneficial to the overall wellbeing of the individual.

2.6.2 Immediate Microsystem

2.6.2.1 Role of the family in meeting unmet informational needs

Young people who have a parent with a NCD, cancer or psychological problem can have difficulty in accessing resources which could ameliorate their unmet psychosocial and supportive care needs. The findings of the systematic review highlighted the role that the young adult's family plays in the deliverance of psychosocial and supportive care. Results highlight the child's desire for information and consultation with their parents, yet the papers suggest that the child does not want to worry their parent through questioning them or talking about their fears [3]. Research has highlighted that parents desire to protect the child from information about their condition (Kennedy & Lloyd-Williams, 2009_b), this could be due to their sensing the child's desire for positive news (Kennedy & Lloyd-Williams, 2009_a), down to feelings of guilt that they are responsible for the situation, or as a result of transference within the dynamics (Leiper & Maltby, 2004). Parent child transference could be conceptualised in reciprocal roles (Ryle, 1990) of protector/protected, with both parties trying to protect the other, possibly due to projection impacting upon the system's ability to be open for fear of causing visible distress.

2.6.2.2 Role of the family in meeting unmet supportive care needs

The papers reported that the adolescent children needed to talk to their family about the emotional impact, potentially helping them cope by reducing stress [2]. Being included within discussions would afford the adolescent child information and increase their perception of family

cohesion [2], thus impacting upon their sense of family security and stability (Baer, 2002). This would likely open dialogue and reduce catastrophising thoughts (Baumeister & Leary, 1995). Spending time together as a family during recreation [3], parental hospitalisation [2], treatment and side effects [3] were needed, increasing stability, adaptive coping and time for the adolescent child to be introspective and spend family time together where they could feel cared for.

2.6.3 Detached Microsystem

2.6.3.1 Role of the school and peers in meeting unmet informational needs

Young people who have a parent with a NCD, cancer or psychological problems can have difficulty in gaining access to needed resources through social or informational barriers. The findings of the systematic review highlighted the role that the young adult's school plays in the deliverance in psychosocial and supportive care. Students received information about cancer within the general curriculum from their teachers. It was based upon biological, genetic and statistical information, symptoms and mortality [1]. School curriculum provides factual information [1], which is held as beneficial in the early stages of the illness experience [4]. The duration of length and stage of parental illness within study [1] varied between one to four months, which could be suggested as being in the initial stages of the illness experience, it could be suggested that curriculum based information would not meet the informational needs of adolescent child students who had parents whose illness were at later stages and duration of the illness experience [4]. Receiving appropriate information at appropriate timings was needed by children [1,5], this is corroborated by the findings of the authors in study [4].

School learning provides information about future health and heritability for the family and child, which was requested by daughters [1,3,2,4] (Hilton & Elfert, 1996; Wellisch, 1981), yet

gender specific cancer means that sons wouldn't have the same concerns. By investigating only breast cancer, the literature was biased. Breast cancer is more overtly linked to daughter heritability and in general there were more daughters than sons within the adolescent child participant sample. Although factual information was beneficial, the young adult children needed information about survivability [1,7], feel good stories [3], and then as time went on, information about the practical things they could do [4] in order to help. There appears to be a dichotomous relationship between the desire for honest information [2] and being given gentle, filtered information and positive news in order to reduce distress [2,4], this discrepancy could go some way in explaining parental fears in disclosing information.

2.6.3.2 *Role of the school and peers in meeting unmet supportive care needs*

Schools do not only open up the child's availability to informed adults, but also increase access to peer groups and potentially other young adults who have an ill parent. The children want to be able to be in a 'normal' friendship where they can rely upon others, and be relied upon by their friends [5], being essential to the attachment process (Bowlby, 1969; Erikson, 1968). Findings indicate that children required social support through support groups to increase coping either by receiving information about how to practically help [4] or through being able to regain some normalcy [1] and in finding compassion [1]. The papers noted some discrepancy between desired social input as there was a need for acknowledgement of their circumstances [1,6], but also the desire to be left alone and not constantly questioned about their circumstances [1,6]. Faith was mentioned in one paper [3]; the access to support through religious belief could not only help with adaptive coping, but also increase accessibility to information and supportive groups.

2.6.4 *Informed Mesosystem*

The findings of five included papers [3,4,5,6,7] within the systematic review suggest young adults require contact and communication with healthcare professionals.

2.6.4.1 *Role of clinicians in meeting unmet informational needs*

Meaningful communication with clinicians [4,7] was needed, and could meet many different needs. Twenty-seven percent of participants in study [7] had a long-standing need of contact with a clinician. Being able to talk with clinicians could meet informational and practical needs regarding how to actively help the ill individual. By having time with a clinician the adolescent child would likely feel included, respected and acknowledged [6]. This could help reduce stress (Hobfoll, 1989) and increase emotional wellbeing.

2.6.4.2 *Role of clinicians in meeting unmet supportive care needs*

Two papers [3,5] found evidence to suggest that clinicians could meet some of the adolescent child's supportive care needs. Being able to talk to an individual outside of the family circle was noted in one paper as being an important unmet need, which could help ameliorate worry by being able to discuss issues without the fear of upsetting family members [3]. The authors of one paper found that young adults required coping strategies [5] to help them, and their family, in managing the changing situation. By being able to explore their feelings and understandings about their parent's illness they would be able to unburden themselves of some psychological and emotional discomfort. This could help the adolescent child feel proud about their contribution and coping, thus potentially turning their input into a gain, thus reducing stress (Hobfoll, 1988; 1998).

2.7 IMPLICATIONS FOR COUNSELLING PSYCHOLOGY PRACTICE

The findings of this review indicate that adolescent children who have an ill parent have frequent and varying unmet psychosocial and supportive care needs. Research suggests that as there is an association between negative affective state and stress with the number of unmet psychosocial and supportive needs [7]. This association has been echoed in research upon unmet needs and burden in spouses, formal and informal adult caregivers (Given *et al.*, 1992; Morasso *et al.*, 1999), thus supporting the case for increased services and recognition of all family members when a parent enters the clinical environment for diagnosis or treatment. By ensuring that questions about an ill individual's family situation were asked during clinical assessments, it implies that assistance for adolescent children is a standard service, and not being offered because they're not coping well with the situation.

Counselling psychologists are well placed within organisations and the NHS to provide needs-based interventions with young adults who have an ill parent. This would be beneficial in assisting adaptive adjustment during the illness experience and also for the prevention of future psychological and emotional hardships (Watson, *et al.*, 2012). The interventions provided by counselling psychologists and the experiences of their clients would help to create increased knowledge and literature which could be beneficial to informing policy and improving practice.

2.8 STUDY CRITIQUE AND EVALUATION

To provide an objective evaluation of this study, the review has been critiqued by using the CASP (2006); the same tool used for quality assessment of the included studies. This chapter posed clearly focused questions, construct of measurement and population under investigation. The included papers were double screened to determine that their inclusion was valid and that their quality was sufficient to allow contribution, yet quality scores were not duplicated by a

separate researcher. Electronic databases and reference lists of included papers were screened to afford a greater breadth of searching. Due to resources, foreign language papers were not included and private correspondence with experts and published authors were not followed up; this potentially reduced the amount of papers which were available for contribution. Results were synthesised and displayed in a table, each item was independently and comprehensively recorded thus increasing transparency and providing an audit trail. Even though the types of illness could be considered to be heterogeneous, the homogenous aspect of this investigation was unmet needs which were present across all illness subtypes. Variations between results were noted in the results and discussion. The population studied within this review were of Western culture and varied in age between 10-24 years. It could be argued that the variation in ages could produce a more varied range of unmet needs, as could the duration of the parental 'illness', yet these were reported where-ever possible. The review's outcome considers the impact of unmet needs and the provision of these needs from many different perspectives, systems and theories. The findings of this review support the need for further research into this area due to current published literature being sparse. Findings give evidence to the implementation of needs-based interventions which aim to target the unmet psychosocial and supportive care needs of young adults who have an ill parent.

2.9 FUTURE RESEARCH

Research suggests that parental reports underestimate the affect of illness upon the adolescent child (Lewis, *et al.*, 1985), potentially being due to the family wanting to protect one another and themselves, possibly as a product of transference. This may impact upon dynamics and routes of adaptive and honest communication. This study highlights the need for more research which

investigates the adolescent child's experience of having an ill parent and their conceptualisation of their unmet needs and the impact that these unmet needs have upon their experiences. It is suggested that further research investigating the adolescent child's phenomenological experience of unmet psychosocial and supportive care needs whilst having a parent with a chronic condition would be beneficial in determining need-based interventions.

2.10 CONCLUSION

The search results of this review demonstrated a lack of literature focusing upon the lived experience and conceptualisation of unmet psychosocial and supportive care needs of adolescent children when they have a parent with a NCD. The findings suggest that young adults have a variety of needs which are not being met, and that unmet needs are positively associated with negative affective state. This highlights the importance in meeting needs in order to protect the adolescent child from current and future biopsychosocial and emotional hardships (Watson *et al.*, 2012).

The individual's needs, access to having them met, and appraisals of the illness situation could all be conceptualised as being moderated by symbolic interactionism (Blumer, 1969) and ecological systems (Bronfenbrenner, 1979) as the adolescent's immediate social group were available to help inform understanding and conceptualisation the illness experience; through this social process the young adult's reality of the situation is created. The review highlighted the positive aspects of the illness experience, such as becoming closer as a family and feeling more prepared to practically cope with more adult tasks; increasing their ability to take responsibility for themselves and others.

CHAPTER THREE

ABSTRACT

This IPA study investigates the unmet needs of seven young adults who have a parent with a non-communicable disease (NCD). Analysis suggests there are four super-ordinate themes – two being related to intrapersonal needs (*The Need for Acknowledgement, The Need to be Themselves*), and two related to interpersonal needs (*The Need for Information, Social Need*), each theme had its own number of sub-themes. The analysis suggests that adolescents had various unmet needs which were similar to adolescent children who had a parent with cancer, therefore this analysis deemed the Offspring Cancer Needs Inventory (OCNI; Patterson, et al., 2010) an appropriate scale for adolescents who have a parent with a NCD.

The analysis highlights the emotional impact that can occur when individuals have a parent with a NCD and suggests that practitioner psychologists are well placed within primary and secondary health care settings to provide needs-based interventions. Further research investigating the associations of unmet needs with affective state and well-being is recommended, for this it is proposed that quantitative analysis is best placed.

KEYWORDS: unmet needs, non-communicable disease, adolescent children, interpretative phenomenological analysis.

CHAPTER THREE
THE EXPERIENCES AND CONCEPTUALISATIONS OF UNMET PSYCHOSOCIAL
AND SUPPORTIVE CARE NEEDS OF YOUNG ADULTS WHO HAVE A PARENT
WITH A NON-COMMUNICABLE DISEASE:
AN INTERPRETATIVE PHENOMENOLOGICAL STUDY

3.1 INTRODUCTION

3.1.1 *Background*

The systematic literature review in Chapter Two found a lack of literature surrounding the lived experience of unmet psychosocial and supportive care needs of young adults who have an ill parent. The results demonstrated that research is important in this area of investigation, as unmet psychosocial and supportive care needs are associated with negative affective state, stress and anxiety (Patterson, *et al*, 2010). Due to the lack of first person accounts within the published literature, this study will qualitatively investigate the phenomenological experience of adolescent children's unmet psychosocial and supportive care needs when they have a parent with a NCD.

3.1.2 *Gender differences*

The findings from Chapter Two suggest that daughters had concerns about their genetic predisposition in getting their parent's condition and required information about heritability, chances of developing the illness and further tests. This could be due to the studies investigating maternal breast cancer, thus being more readily linked to daughters than sons, and due to there being more daughters than sons as participants.

The term gender can encompass many different concepts, from biological meaning through to social and cultural constructions of the concept. Generally societal understanding has a very definite split between male and female orientated roles, (i.e. women caring, child rearing, and male's bread winners and 'leaders'). It is likely that societal understanding and upbringing regarding caring, coping and emotional response has some of its basis routed in gender roles.

3.1.2.1 *Gender differences and the caring role*

Owing to societal concepts leaning more towards females undertaking a caring and supportive role (Stone, Cafferata & Sangl, 1987) and being more able to deal with emotional concepts, research has shown that daughters are more likely to become their parent's confidant, putting them at an increased risk of becoming depressed (Bauman *et al.*, 2001). By becoming a confidant, the daughters would likely have to contend with new physical tasks and increased insight into their parent's distress, thus impacting upon their affective state and wellbeing. With social roles more readily aligning females with caring roles, parentification, being defined as the child becoming the parent to the parent, would likely be more readily associated with females. Parentification would also influence the caring dyad, and it is likely that ill parents would be happier with daughters caring for them as it already falls into a caring archetype role. Disruption within the family dynamics, safety and stability can increase psychological and emotional hardships for the adolescent child due to the need for parents to be a secure base and provide a stable home-life (Bowlby, 1969; Berndt & Perry, 1986), and due to them not being emotionally mature enough to be able to manage their own and their parent's distress.

Adolescence is an important time for identity formation (Erikson, 1968). Douvan and Adelson (1966) suggest that identity is subject to gender differences. Females have interpersonal identity,

and males intrapersonal identity (Sroufe, Egeland, Carlson, & Collins, 2005), this means that females identify themselves based upon their role with a social context; this could make them more comfortable at taking on a social role, such as caring. Males identify themselves based upon intrapersonal beliefs, making them internalise their actions and feelings, it is likely that this would bear an influence upon an individual's coping and defence mechanisms during difficult times.

3.1.2.2 *Gender differences and emotional defences*

Brody (1985) theorised that gender plays a role in the way in which emotions are regulated, suggesting that as the individual increases in age, males inhibit emotional expressions and aetiology, and females inhibit the expression and recognition of socially unacceptable emotions, such as anger. The social acceptability of emotional expression could also likely impact upon an individual's ability to 'offload' and the way in which they begin to conceptualise, accept and work with any emotional discord. This was further evidenced by Piko, Keresztes, and Pluhar, (2006) which investigated emotional coping in adolescents aged 14-19 years. It was found that boys are more likely than girls to use projective and aggression-outward defence mechanisms where as girls internalise and turn against the self, potentially fitting in with socially acceptable methods of emotional expression, yet whether these are biologically founded or borne through social learning is debateable. Conte & Plutchik (1994) coined the term 'planification' to denote the use of more mature defence mechanisms such as sublimation, intellectualisation, rationalisation, and annulation as a means to adaptively cope, yet no gender differences were noted.

As aforementioned gender differences could be due to biopsychosocial and cultural influences in emotional development. It could be suggested that adolescent sons and daughters who have a parent with a NCD would have different ways of communicating, coping with and conceptualising emotional hardships. The differences in communicating distress may moderate the accessibility to social support as individual's defences may mask the emotional and psychosocial needs of the adolescent child (Goffman, 1959). Goffman (1963) suggest that individuals present a different social facade to the world in order to protect and disguise their inner psychological and emotional affect. This too would likely have an impact upon the adolescent child's conceptualisations about the illness due to symbolic interactionism being based upon a socially created reality (Blumer, 1969; Goffman, 1959; 1963).

3.1.3 Family

The young adult's family can provide access to a variety of different needs which would otherwise be left unmet. The analysis from Chapter Two suggests that families try to protect each other from any additional upset through not discussing issues within the group. Literature suggests that protection is due to parents not feeling equipped or ready to discuss the subject with their child as they were fearful of upsetting them (Kennedy & Lloyd-Williams, 2009b), the transference of this protection was noted by adolescent children as they did not want to worry their parents. The analysis from Chapter Two suggests that some adolescent children wanted to have honest and age appropriate information and others wanted to have information given to them gently (Handley, *et al.*, 2001; Kennedy & Lloyd-Williams, 2009a), this could make information sharing a difficult balancing act for parents and clinicians.

The transference of the taboo illness subject within the family would make discussion difficult. Chilling behaviour (Afifi & Olsen, 2005) looks at how individuals refrain from voicing opinions for fear of upsetting family dynamics; this seems to be comparable to the experiences of the young adults in their restricted social voicing of concerns, thus creating a cycle of concealment (Afifi & Olsen, 2005) where individuals are not able to open themselves up for assistance thus remaining stuck in the sequence.

3.2 RESEARCH QUESTION

Findings in Chapter Two highlighted the lack of research investigating the first person account of the psychological and emotional impact of unmet needs upon adolescent children. This study will investigate question two of this thesis.

Question 2: What are the experiences and conceptualisations of unmet psychosocial and supportive care needs of young adults who have a parent with a NCD?

Participant data will be collected through the use of semi-structured questionnaires. Interpretative Phenomenological Analysis (IPA) will be used to analyse the data as the research question explores the young adults' in-depth lived experience and conceptualisation of their unmet psychosocial and supportive care needs, whilst having a parent with a NCD.

3.3 METHOD

3.3.1 Design

This research question can only be answered by taking an in-depth analysis of the individual's experience. Qualitative methodology lends itself well due to the ability to generate rich data,

something which is otherwise lacking in the current literature. Interpretative phenomenological analysis (IPA) is a thematic approach to analysing participant's narratives which is especially suitable for understanding their phenomenological experience and the meanings they conceptualise from this. Such depth of understanding may not be achievable using other qualitative methodologies, it is necessary to address this gap in the literature in order to develop effective and relevant needs-based interventions and to inform further research.

The IPA researcher plays an important role through double hermeneutics (Storey, 2007). This mode of analysis lends itself well to the philosophical underpinning of counselling psychologists as IPA combines empathic and critical hermeneutics (Ricoeur, 1970). Counselling psychologists are trained in being able to empathically connect with an individual's narrative and to notice inconsistencies and challenge without judgement (Woolfe, *et al.*, 2003), which is a premise of IPA research.

3.3.2 Participants

An homogeneous sample of seven young adults (5 female, 2 male), aged between 17 and 19 years old were recruited from institutes of further and higher education (see table 3.1 for demographic summary). The young adults were informed about the study at their colleges and universities via poster advertisement (appendix 3.2). An opportunistic sample was recruited (i.e. the first seven responses which fitted the inclusion criteria). The inclusion criteria stipulated that the young adult offspring had to have a parent who had been diagnosed as having a chronic illness by a medical practitioner (the term chronic illness was used as opposed to NCD, owing to it being more readily understood). They had to either currently live with their parent or spend at least two days a week with them. The sample included children of parents with a range of NCDs

which had been diagnosed between three months and eighteen years prior. IPA favours recruitment of homogenous samples. Whilst this sample was heterogeneous with respect to illness, the common feature of interest – the care-giving experience and unmet needs – was shared between all participants, thus meeting this requirement. The idiographic nature of IPA allows for individual differences in themes to be explored between these illness types.

Table 3.1 Showing participant demographics

Participant Pseudonym	Age	Ill parent and illness type	Family Dynamics	Time since diagnosis
Kathleen	17	Mother – Migraine	No contact with father previous cancer diagnosis. Sister, Kathleen and mother live together.	10 years ago
Julie	18	Mother – arthritis	Only child. Lives with mother and father.	8 years
Paul	18	Father – Epilepsy	Lives with mother, father and 3 siblings.	8-9 years
Jason	19	Father – Diabetes	Lives at home with parents	6 months
Heather	18	Father – Renal failure leading to kidney transplant	Lives with boyfriend	18 years
Carly	17	Mother – Polycystic Kidney Disease (PKD)	Lives with parents and brother	15+years
Jayne	18	Mother – Myalgic Encephalopathy (ME) / Chronic Fatigue Syndrome (CFS)	Only child. Lives with parents.	3 months

3.3.3 *Materials*

A semi-structured interview (see appendix 3.1) containing 11 questions and prompts was developed from information derived from the findings of Chapter Two. The schedule was not designed to be linear; rather its sequence was directed by the course of the interviews (Smith, Flowers & Larkin, 2009), though the interviewer ensured that dialogue was raised in each area of the schedule. The questions were non-directive thus allowing the participant the opportunity to reflect upon their own personal experiences and to govern the direction of the interview within the guidance of the schedule. All interviews were audio recorded for transcription purposes. In

the case of sound interruption, ambiguity or interference the researcher would leave the interfered section as inaudible.

3.3.4 Procedure

This study gained ethical approval from the University Ethics Committee. After receiving details of the study by poster advertisement, potential participants were required to make direct email contact with the researcher, where they gained access to the information sheet (appendix 3.3) and were able to ask any questions. Interviews were conducted on a one to one basis and were arranged to take place at a mutually convenient time, in a private room at their place of study. Before the commencement of the interviews, participants were given the opportunity to re-read the information sheets, to ask any questions and fill in a demographic sheet (appendix 3.5). Written, informed consent (appendix 3.4) was then obtained and the interviews began. After the interviews were complete and the audio recording had ended, participants were given the opportunity to ask any remaining questions they had. The participants were debriefed at the end of the interview and given debriefing sheets to take away with them (appendix 3.5). Interviews (appendix 3.1 of confidential attachment) lasted between 30 and 85 minutes. The recordings were transcribed by the researcher on a password protected computer; pseudonyms were used to protect participant identity. The raw data recordings were destroyed in order to protect individual's details as they had disclosed the name of their friends, school, family members and medical practitioners.

3.3.5 Analysis

IPA analysis is flexible as opposed to prescriptive in its approach (Storey, 2007). Each interview was transcribed verbatim following guidance by Smith (2003). These guidelines advocate the

interview questions, all respondent false starts, laughs and pauses are included in the transcription. The transcripts were read on multiple occasions to gain a holistic overview, ensuring the analysis remained grounded within the participants' phenomenological experience. Initial themes were recognised and refined, thus leading to the researcher's interpretation of the participant story (Smith & Osborn, 2003).

In accordance with IPA recommendations, transcripts were then independently analysed by the researcher and an independent researcher, Sam Flynn (SF), a graduate level research assistant. This involved each researcher independently reading and re-reading the transcripts and identifying emerging themes. These were then compared and the two analyses were formulated into a joint thematic framework devised by the researcher, SF, and the supervisors collaboratively to ensure that the framework and researcher interpretation was as valid and unbiased as possible. The inclusion of a second researcher to interpret the transcripts increased rigour as findings were merged into a joint thematic framework to increase the robustness of the data.

Yardley (2000) suggests that there are four principles for assessing quality, these being: sensitivity to context; commitment and rigour; transparency and coherence; and, impact and importance, which are essential to robust research. An audit trail of emergent themes, linguistics, commonalities and divergences were created and subsequent table of themes with supporting evidence was constructed (appendix 3.7).

3.4 RESULTS

IPA guidelines suggest that themes are arranged into a framework of super-ordinate themes which act as a categorisation for associated sub-themes (Smith, et al., 1999). Within these data

four super-ordinate themes, two relating to interpersonal needs and two to intrapersonal needs, respectively: Information Needs, Support Needs, Need for Acknowledgement, and the Need to be Them-Self each with their own number of sub-themes emerged. These are summarised in Table 3.2. Exemplar quotations from participants' transcripts contextualising the analysis will be placed throughout the results section. To retain anonymity participants are referred to throughout by pseudonyms.

Table 3.2 Showing Super-Ordinate and Sub-Ordinate Themes

Super-Ordinate Theme	Sub-Ordinate Themes
Need for Information	Availability of Honest Adult Information; Information and Emotional Response; Desired Information; Medicalised Information as a means to Normalise; Medicalised Information as a means to Control Emotional Response; Medicalised Information for Future Control.
Need for Acknowledgement	The Secret Carer; The Ignored Carer; The Credited Carer.
Support Needs	Compassionate Support; Required Assistance; Friends, Family and Recreation; Social Understanding.
Need to be Them-Self	Introspection and Escapism; Internalised Pressure; Emotional Impact; Illness Cycle; Roles; Protector of Others; Duties; Unacknowledged Coping through Practical Diversions.

3.4.1 Need for Information

A continuous theme throughout each participant's transcript was the individual's need for information. Information fulfilled many different functions for the young adults and each super-ordinate theme was related to the powerful influence information played in the lives of the young adults who were taking on a caring role. There is a strong sense throughout all of the sub-themes

that information affords the young adults a sense of power in and over a situation where there is little to no control.

3.4.1.1 *The Availability of Honest Adult Information.*

This sub-theme was conceptualised through a distinct feeling that the young adult had to battle and work hard to furnish themselves with the information they required. There was an apparent difference between the ‘classification’ of child and adult. The young adults were doing an adult role, but being given ‘child’ information. The discrepancy and incongruence between ‘being an adult’ and ‘understanding as a child’ did not help the young adult in their response to their parent’s diagnosis, subsequent prognosis, or the new roles within the daily living of their family unit.

“when I first heard that Dad was ill, I looked it up at the school library and took it from there”

[Paul, T3, lines 295-296]

“Was I supposed to get her warm or cold drinks, what foods should she eat, I’d heard of trigger foods, but had no idea of what they could be. Information is not available to like us [sic]”

[Kathleen, T1, lines 455-458]

Kathleen’s extract exemplifies the role of information in helping guide her through the unfamiliar situation. Information was conceptualised as helping the adolescent feel more grounded and “a bit more with it” [*Julie, T2, line 175*], indicating that information affords a sense of control and certainty of where the illness could take the family.

There was a strong sense that this battle was unjust as the young adults were doing the caring, caring for themselves, but not being catered for by professionals or society, and that the truth was unlikely to be as bad as their fears. There was a noticeable feeling of the young adult being disregarded and excluded from the illness event. They did not fit into any specific category or under the care or protected guidance of another knowledgeable and trusted individual, increasing feelings of uncertainty.

“I wasn’t supposed to know”

[Jayne, T7, line 313]

This was compounded by the young adults being sheltered from honest, adult information. The more protected they were, the worse they believed their parent’s condition to be.

“By them being evasive, I thought there was something to really worry about and that they were trying to protect us...yeah, er, crazy really”

[Kathleen, T1, lines 876-878]

“I knew that the leaflets wouldn’t lie or make it sound better than it was. They would be truthful.”

[Julie, T2, lines 163-165]

The above extracts highlight that by being protected, the young adults fear the worse, when this is coupled with the lack of honest, adult information they begin to catastrophise the situation into believing it is worse than reality. Julie feels very much alone and unable to turn to any trusted

individual, as such there was a sense of relief and trust in literature that had been designed for those in their situation, but not specifically for them.

Being given honest and trusted information and details about their parent's condition was invaluable because the mismatching of information often resulted in a self created reality which was worse than real life.

*“I looked on the internet when I was about 12 and I thought she
had a brain tumour”*

[Kathleen, T1, lines 654-655]

The impact of the young adult being given inadequate information is evident. They believe that reality must be worse than their initial beliefs and they understandably begin to catastrophise the situation, with the effect of making it worse than reality.

3.4.1.2 Information and Emotional Response.

Young adults use information to steady themselves, yet when they try to use this coping tactic within their family unit, it does not always offer the relief they desire. The role information plays can be one of a soothing nature. The young adults wish to be informed and as such they begin to work through the information to help them get a truer perspective of the situation.

*“mum told me what it was and I felt so relieved. I cried that
night as I was so relieved.”*

[Jayne, T7, lines 326-327]

The emotional relief at having information is evident in the above passage, yet some of the relief is being talked to by the family. The inclusion allowed Jayne to see her family come together and she felt a part of the family unit, affording her a sense of self and security.

Even though the young adult was scared of what they may discover, they felt compelled to get the facts, no matter how painful they may be.

*“I started reading only bits, as I was scared that it would say,
but, er, I used to read them over and over again”*

[Julie, T2, lines 167-169]

Once information has been received there was a desire to talk and be open within the family; the subject has been acknowledged within the family forum and is open for discussion. However this can negatively impact upon the emotional state of the young adult when they feel as though their enquiry or information is upsetting their family.

*“he’s not interested and mum just got a bit upset, well like
pissed off that I was showing it her”*

[Jason, T4, lines 183-185]

There is, however, also the potential that information can have a negative effect as the long term reality of the situation hits home.

*“I coped better when I thought she had the flu...Err, I
know what flu is and I know that you only have it for
a while.”*

[Jayne, T7, lines 444-448]

Whilst the young adults have been asking for the truth, once it is received the long term emotional and psychological effects begin to make themselves known. Jayne first felt relief that her mother did not have a terminal illness, yet as she begins to think of long term effects of the illness she realises that her mother will have lapses in her health. The initial illness fear of it being Leukaemia is forgotten and the illness is compared against flu which is more time limited, common place and less threatening, this impacts upon Jayne conceptualisation of the unfairness of her new life and the endurance and gravitas of the experience.

3.4.1.3 *Desired Information*

All of the young adults stated the importance of information, yet its type and purpose varied. Information which could help inform the social group of the young adult was conceptualised as important, with the end goal of increasing emotional or practical support.

*“I wish that the doctors could have given me something to give
my teachers”*

[Kathleen, T1, lines 695-696]

The role of society giving information is exemplified in a narrative by Kathleen.

*“Why didn’t anyone think about talking to us
about all of this stuff, like if we were old enough to care, surely
we were old enough to understand?”*

[Kathleen, T1, lines 465-468]

The tone of anger and disbelief is unmistakable; it highlights the obviousness of their role within the family and their hidden role within society. There is a prominent need to talk to someone and

have human contact, specifically for them, where the young adult could have some of their questions answered and have a sense of being included.

The power which comes with information and the young adult's increased knowledge helps them to feel more in control not only of their emotions, but also the situation. They no longer feel passive.

*“I think my doctor, you see they would be able to give me the
medical stuff and like help me understand what is and isn't
making it better and worse.”*

[Jayne, T7, lines 614-616]

The need for medical information and its impact upon the young adult's self confidence is identified as a need; the collaborative interaction between young adult and clinician would afford the individual a sense of importance, stability and being grounded. Having contact with a clinician would be able to give them access to information which they would not otherwise be able to obtain, thus helping them manage the illness situation.

The emotional impact of having an ill parent is evident in the narratives of the young adults, but in addition to this they also worry about their own future, wondering if their parent's illness and the situation will be their destiny. Information is not just beneficial for the present, but also has the ability to inform the young adult about their future, giving them some control and acknowledgement of the various ways the illness has impacted upon their lives.

*“I suppose it would have been good to know what
the chances were that I was going to get it”*

[Julie, T2, lines 553-554]

The fear of inheriting the illness is something which the young adult would like more information about, yet there is a sense of embarrassment in their having this question, due to their fear of sounding selfish, or fear at discovering the facts and possible impact upon their future.

3.4.1.4 *Medicalised Information as a Means to Normalise*

Throughout the participants' narratives there was an obvious use of medical language. The medicalisation of the illness and treatment potentially assisted the young adult to normalise the situation, illustrating that others are in similar circumstances and specific literature surrounding the physiology has been created.

*“After she’s been sick for a couple of days her joints feel better,
like they don’t have grains of sand in them, that’s something to
do with toxin build up as the kidney’s aren’t working properly.*

Then after all that she’s ok again”

[Carly, T6, lines 170-175]

The young adult is making sense and making safe the threatening situation of her mother's kidneys not working properly by conceptualising it as a circular event. This conceptualisation helps Carly understand the typical nature of the illness and that there is some normality in the cyclical nature of the condition and this familiarity about the event affords her some feelings of control.

The concept of the control an individual can feel in medicalised language is further exemplified by the following extract. The medical nature of their discourse is used as an intellectualised

defence mechanism which activates to repress negative cognitions and emotions when the individual's anxieties regarding their parent's condition becomes too painful and real.

“It can be really dangerous, but very easily treated. I was a bit worried that he could have a fit and cause some serious damage, but his tablets have stabilised his condition well.”

[Paul, T3, lines 298-301]

The linguistic pattern allows the individual to acknowledge some of the emotional distress, then use jargon and ‘medical’ faith in helping relieve their anguish.

3.4.1.5 *Medicalised Information for Future Control*

Another important function of the medical terminology is its predictive powers surrounding patterns and future events surrounding the illness.

“you can prepare yourself or if it's not going to happen and then you can just relax and not have to worry about it.”

[Heather, T5, lines 143-145]

Heather intimates that medical information helps her feel in control of the future by being able to prepare irrespective of the outcome. Knowing and planning is better than free falling and that information in its many forms and guises helps the young adult feel empowered to continue and accept the situation that they and their family find themselves in.

3.4.2 *The Need for Acknowledgement*

Another theme which emerged through the analysis of the transcripts was the need for acknowledgement. There was an underpinning of responsibility, yet it was not always unwelcomed but willingly undertaken by the offspring. Along with this new caring role came a felt sense that their physical and emotional energy was not credited by others.

3.4.2.1 *The Secret Carer*

The first premise noted in this super-ordinate theme was that of *The Secret Carer*. There are many different facets and aspects to this theme. The adolescent children felt that they had begun to identify themselves with other carers, yet they were a secret kept from societal awareness.

*“There really should be something to help carers, but I er,
suppose like er, I’m not a carer, I’m just looking after Mum”*

[Kathleen, T1, lines 866-868]

There is identification with the label of ‘carer’ yet they do not feel that it is validated through societal concepts. The linguistic use of ‘just’ belittles Kathleen’s role in her parent’s illness, paralleling her internal concept of how she feels marginalised by society.

*“I think that there are loads of people having to look after their
parents but it’s never spoken of,..it’s like we don’t exist”*

[Carly, T6, lines 744-747]

Carly’s extract also highlights society’s lack of understanding; it suggests that part of the young adult’s identity is now that of a carer. This lack of acknowledgement is another social and informational barrier faced by the young adult.

The secrecy of the concept of young adult carer in today's society is further elaborated upon by Carly who conceptualises the status of 'child' carers as a dichotomous construct of either being kept, abused by being forced, and exploited into the caring role by being in an unhappy and dysfunctional family, or living in a normal world, with only the 'abused' warranting societal compassion.

“child carers how many times do you hear it on the news, the only time you read about it in the papers is when a child has been abused or mistreated...well we haven't so it's almost like it doesn't matter”

[Carly, T6, lines 754-758]

The secret emotional impact of the parental illness is highlighted in the following extract. The secrecy of the young adult's actions illustrate the level which he feels he has to reach in order to get answers to his questions and to determine if his fears that his father is not keeping to his new diet and healthy living regime are justified.

“the other day I drove round the lorry cafes until I saw his lorry parked there so I know he's cheating. “

[Jason, T4, lines 321-323]

Jason feels betrayed by his father's actions. The feeling that his father does not take his health concern seriously makes Jason feel powerless and unable to trust. Part of his caring role, motivated by the fear of his father dying, is to keep the 'caring' secret from his parents so as not to induce worry or anger. Jason feels that he is taking the situation more seriously than his parents, thus leading him to be covert in his actions.

The secret carer also encompasses the secret role of ‘doing’ caring behind the scenes, there is an elusive nature to the young adult’s practical caring duties.

*“I don’t really ever say that I’ve done it, it just, it’s just, like
done”*

[Jayne, T7, lines 206-208]

Jayne describes her performance of tasks with an air of self sacrifice, all for the benefit of her family happiness. The repetition of the word ‘just’ gives the impression that she works hard to create the illusion of not working hard at all, as though the tasks happen as if by magic.

Another aspect of the secret carer is the young adult keeping their felt emotional impact secret from their family in order to protect them from any further upset. The secrecy and the relaxed role she undertakes is more demanding than the physical tasks.

*“how hard I work to try to make it look as though I’m not
stressed”*

[Carly, T6, lines 643-644]

The above extract illustrates how the young adult is working hard to make it look as though she is not stressed. In order to protect her family group she displays a calm mask to the world whilst her internal reality and sense of self is in turmoil. Carly may feel as though she has to be very strong as her mother has a serious condition, increasing the weight of her responsibilities as the situation could rapidly become life threatening.

3.4.2.2 Ignored Carer

The extracts thus far have seen how the young carer works hard to make their parent's illness impact a secret; there is the paralleled response from the parents who are unable to see the impact upon their child. The young adult is adept at hiding their emotional impact and the parents accept this as truth. Parental defences act as a protective factor to block their child's distress. The emotional impact of being ignored is illustrated by Jayne whose extract is one of anger and sheer bewilderment at the situation that the family are in.

“They ignore me. They think I’m selfish. But I try not to worry them by them feeling guilty at all the stuff I’m doing and the way its ruining, ruling my life.”

[Jayne, T7, lines 373-375]

Jayne's emotional outburst allowed for her true feelings to come out when she said 'ruining' which she quickly changed to 'ruling' her life. The way in which her parents misunderstand her actions at being very discreet in the tasks she performs and the emotional impact it has upon her has made the parents believe that she is selfish, thus making Jayne feel even more misunderstood and alone than before; being damned if she does and damned if she doesn't. She self sacrifices for 'the greater good' of their family.

“tell mum what’s best. I think she thinks I’m doing it for me, but I’m doing it for dad.....but that’s fine, as long as it affects them I don’t really care what they think”

[Jason, T4, lines 364-367]

Once again the young adult manages to reduce their parent's emotional impact by allowing themselves to be misunderstood for the benefit of their family's health and coping. The effect of

being misunderstood, although fulfilling its purpose of certain groceries being replaced by healthier ones, affects Jason. The long pause in his speech followed by the statement that it was fine conveys a powerful message that it is anything but and that he has been misunderstood and lost within his family unit.

The transcripts suggest that the young adults work hard to help their family, yet they are desperately in need of help themselves. The more they protect their family through the secrecy of their caring, the more people believe that there is not an issue, thus increasing the young adult's angst at trying to protect everyone by putting on a brave face.

*“I did and do all this stuff to help and at times I wondered if
they really knew that I needed to help.”*

[Julie, T2, lines 483-485]

3.4.2.3 *Credited Carer*

Another aspect of this sub theme is the young adult feeling credited for the work which they do. The extracts contained within this theme illustrate the young adults' emotional and practical struggles within their family unit.

*“Nan would look after her to start off with, but as I got older I
just copied what Nan did, er, until Mum said that she didn't
need Nan”*

[Kathleen, T1, lines 645-647]

The young adults fall into their caring role and their ability to make things look calm and manageable conveys the message to their parents of being able to cope. The family duty of

caring for ‘mum’ got passed to the daughter when her grandmother got too old; caring was now an implicit role for Kathleen to undertake. This family duty also transmits to Kathleen’s sister, yet Kathleen does not feel that her little sister is able to cope with the physiological and emotional demands, potentially reflecting her own feelings at undertaking the caring role and her desire to protect and care for her younger sibling.

The lack of recognition, importance and the seemingly unnecessary nature of the tasks within the family unit are apparent in the following extract. If Carly doesn’t do the tasks, they could get completed by someone paid to do it. This statement places a monetary value upon her caring. She cares, yet is replaceable either by a ‘professional’ or by her brother when she leaves home. The meaning behind her caring, being her love of her family seems to have been lost within the parental conceptualisation of the situation.

*“If I didn’t do it, Dad would pay for someone. It’s like my role
now, then it’ll be XXX [brother].”*

[Carly, T6, lines 750-751]

The young adults do everything possible to try to reduce the emotional impact upon the family unit, yet this is lost in translation, resulting in the denial of the young adult’s sense of self, making them unable to feel cared for, accepted and contained. This theme gives the overall sense that the young adults are dedicated to their family unit and its harmony, yet their actions are misattributed by society and their sense of belonging, identity and value within the family is multidimensional.

3.4.3 Support Needs

Within this theme the young adults acknowledged a plethora of supportive needs which would help them to cope with and partake in their parent's illness. They conceptualise that society has the power to support and facilitate them in regaining some psychological and emotional equilibrium within their lives, yet it appears that there is a difficulty in trusting societal concepts and interactions.

3.4.3.1 *Compassionate Support*

The young adults are at the mercy of societal understanding in order to gain access to means which could help their coping.

“when I said, like to my friends that mum might have cancer they were all over me, like so protective and supportive...but when I told them she didn't have it, they were, like they were really pleased, but they thought that meant that what she has was just like a cold and she'd get over it, but she won't.”

[Jayne, T7, lines 214-221]

This extract illustrates societal concept over serious illness. Jayne intimated she received support from her friends when they conceptualised the gravitas of the illness, yet when the peer conceptualisation of the illness changed so did their support, yet Jayne's state of pain remained constant, leaving her feeling abandoned and misunderstood.

The following extract illustrates that the intention and interest behind the social support impacts upon the individual's trust to accept help.

“She said that she could arrange for me to talk to someone, bit like you I suppose...but when I got the letter it said there was a twelve week wait, so I thought that actually no one is really that interested”

[Carly, T6, lines 386-391]

It seems from this above extract that Carly would have welcomed the opportunity to talk, yet she was upset at being just another name on a list and felt that her experience was not being validated. It may be that the doctor referred Carly on as she had spoken up, or due to the GP being aware that the condition could worsen. Carly’s experience of social assistance was juxtaposed by Jayne’s, who found compassionate support by being told that any time she needed support she could rely upon her teacher. The recognition offers acknowledgement and support and gives the message that her situation is one which warrants respect and kindness.

“She was really nice to me and said I could go to her at any time I needed to”

[Jayne, T7, lines 532-533]

3.4.3.2 Required Assistance

The young adults stated that they required different types of assistance which they were unable to access. Young adults want to feel included and safe in their family unit, with evidence that the family is still a solid and stable construct.

“We don’t sit down together and you know like just go ov [sic], family meeting (laughs). Nothing like that.”

[Carly, T6, lines 302-304]

The need for inclusion and societal integration is also echoed in Jayne's extract where there is the sense of freefalling by being left alone to cope.

*“you have tests, get told what you've got and get given medicine
to get better. That was a bit of a shock. It was like we were all
left on our own”*

[Jayne, T7, lines 289-291]

Young adults need social contact and understanding for their physical and emotional wellbeing. They require contact with members of society to help give them the encouragement, information and guidance they need to adaptively manage their family situation so they can begin to psychologically and emotionally adapt.

3.4.3.3 *Family, Friends and Recreation*

Adolescence is an important time in human development. The social support and interaction found within peer interaction gives individuals the ability to detach from the parent and attach to their social group (Hazen, et al., 1994). Recreation and time with peers has a dichotomous relationship in the life of the young adults. They recognise the desire to have some time away from their caring responsibilities and to have emotional respite, yet this was only possible once they knew their parent was ok.

*“when he was starting to come out the other side it was nice to
er get away from it all. But for people to not like make me do*

*really outgoing stuff, just like chilled stuff, like go ice skating,
that was always good”*

[Heather, T5, lines 172-175]

The role of the family in the supportive needs is complex, with the young adult taking on many roles within the family.

*“I would like talk to dad when he was away on the phone and
say that she had gone funny again...but to be honest it was
always spoken of as a big inconvenience”*

[Carly, T6, lines 175-180]

Carly feels increased pressure that she could be jeopardising the family unit by telling her dad what is happening at home and emotionally with her. The protective factors of keeping the family safe are put first.

Kathleen’s extract conceptualises the calming and normalising affect that the family can impart during stressful times.

*“we refer to it in strengths, kinda, ya know, how bad it is, so it’s
like ‘last August’, or it’s like ‘Monday’”*

[Kathleen, T1, lines 843-844]

The comfort in stable interpersonal contact can help the young adults’ intrapersonal coping. Contact with friends can be a mixed blessing as there is the impression that the young adult recognises and loves the support and time with their friends, yet as their home situation becomes

increasingly different from the norm, the less supportive they find their friendship group, due to their lack of emotional understanding and empathy.

*“I’m not going out with my friends now coz they’ve got pissed
off with me cancelling or having to leave early”*

[Jayne, T7, 387-389]

The above extract highlights the effect the parental illness can have upon the young adult. Not only does it feel as though they are losing their childhood at home, but also the group of people who they can identify with and reconnect to the world as an adolescent. The need for peer identification and support is essential for the adolescent as they are going through a transitional period and a stressful life event (Berman, Cragg & Kuenzig, 1988; Garnezy, 1991), yet this makes them feel unable to reconnect and as such lose sight of them-self.

The confidence, grounding and reconnection with the real world are essential parts of the supportive friendship group. They were able to accept their friend and allow her to be, without her having to protect them from her discord; they gave her the release she was unable to attain within the home environment.

*“I’d not have managed to do so much stuff if they hadn’t like
pulled me along.”*

[Heather, T5, lines 390-391]

3.4.3.4 Social Understanding

Social understanding plays an important role in the young adult feeling supported and validated in the difficulties of their life. The social concept of the parental illness does not always match

the lived reality. Societal interaction with the young adult has an enormous impact upon their life and the way that they view their situation and their ability to access help.

“people call it yuppie flu, I mean, it sounds really blagger”

[Jayne, T7, lines 78-79]

Jayne’s exasperation is evident in the above extract, as if society misunderstands the illness, they cannot be trusted to comprehend her plight or needs. This concept is echoed by Kathleen who indicates that society bases their notion of worthiness of help upon their understanding of the specific disorder.

“if she had something that sounded more scary, I mean I’m glad

that she, ya know, I’m grateful, ya know that she doesn’t, I’m

sure people would be rallying around”

[Kathleen, T1, lines 231-234]

The young adults conceptualise that society values the medicalised nomenclature of conditions and bases its compassion upon the illnesses conceived severity.

3.4.4 Need to be Them-Self

Another continuous theme throughout the participant’s transcripts is that of the individual’s *need to be them-self* and for them to find some respite. The reconnecting with themselves as teenagers as opposed to carers fulfilled emotional and physiological functions. Each sub-theme related to the powerful internalised pressures they were trying to meet and manage. The sub-themes intimate the desire to reconnect with their old lives, and are coveted potentially as a means of pacifying and taking sense from an uncontrollable situation.

3.4.4.1 *Introspection and Escapism*

A theme which relates to their ‘child’ part is that of escapism and introspection. Whilst the young adults are undertaking adult responsibilities and roles, there was the sense that their ‘child’ part required nurturing.

*“times when I wish I could have been wrapped in a duvet and
sat in front of the fire to watch a movie. Like to just be
comforted and snuggled up all safely”*

[Julie, T2, lines 459-461]

This extract utilises curious dialect. The terms “wrapped”, “comforted”, “snuggled” and “safely” brings to mind child-like times of being made to feel safe and secure during illness. The extract gives the distinct impression that the young adults want their emotional upset to be soothed. The child-like language is indicative of Julie’s desire to feel secure within her family unit, being cared for and looked after as though they were wounded is evident. The language symbolises her being cocooned away from harm with someone else to care and relieve her anguish, this being a comparison to the tasks she is undertaking within her family.

This childhood conceptualisation of escape is noted in Jayne’s extract. She fantasises about being rescued from the situation.

*“if this was a film someone would come along and sweep me off
my feet”*

[Jayne, T7, lines 162-164]

The above is redolent of a fairy-tale ending with Jayne unable to see a way out of this situation without resorting to an overly optimistic fantasy of escapism. Her cognitive or emotional maturity is not robust enough to mobilise and manage her intrapersonal and interpersonal conflicts without resorting to a pretend world where defences are less readily activated.

The extracts thus far have indicated that the young adults feel obliged to put on a brave face, alone time gives them space to be able to process their needs and begin to manage effects without having to monitor their behavioural reaction, thus allowing them to just be.

“I just wanted to escape and be by myself”

[Paul, T3, lines 160-161]

The time for reflection plays an even bigger role when combined with the concept that the young adults have to be more than themselves. They get lost in their new role and as such need time to acknowledge their feelings and needs. There is a paralleling of the theme *need for acknowledgement* in so far that the young adults need to acknowledge themselves, not just their new found task.

*“It’s weird coz when he’s not ill all I do is look and wait for him
to be poorly then when he is ill, all I want to do is like see what
he’s like then get some space to er just chillax.”*

[Heather, T5, lines 326-329]

The felt impact of the illness is exemplified within Heather’s passage as she states that she is on tenterhooks waiting for her parent to become ill. The uncertainly is the only certain part of the

illness, once the family is struck by the affliction she no longer has to wait for the inevitable. Once the tense waiting is over she wishes to retreat and hide as reality has hit.

3.4.4.2 *Internalised Pressure*

Internalised pressure refers to the synergic effect of the young adults unmet needs. The previous theme of *The Secret Carer* exemplifies the internalised pressure which the family dynamics dictate when this is compounded with the lack of support and information, the impact is felt through a sense of uncertainty.

*“I did wonder ya know, that if something went wrong would it
be because I had done something wrong, or forgotten to do
something”*

[Julie, T2, lines 346-349]

Julie’s extract illustrates the felt pressure, the linguistic use of the words ‘wrong’ and ‘forgotten’ are laden with judgement surrounding the young adult’s ability and their belief that they are not good enough.

3.4.4.3 *Emotional Impact*

The emotional impact which the young adult feels has a psychosocial impact. The emotional effect upon the young adults is exemplified in the following extract.

“kinda [sic], lonely, like we are the only ones in the world”

[Kathleen, T1, line 488]

It is evident that increased information and social contact could go some way to remedy this belief by their feeling more empowered and less alone.

*“the horrid tummy butter...turns when I could hear her like
struggling”*

[Julie, T2, lines 216-217]

The physiological response of the young adult during their parental illness is apparent. This being indicative of the helplessness they internalise whilst trying to show a very calm and aloof external picture to the world. They do not feel as though they have the resources to help, yet feel responsible that it's their job to ensure their parent is comfortable.

The previous theme of *Medicalised Information as a Means to Control Emotional Response* suggests that the young adult get a sense of control through having access to knowledge about their parent's illness. Due to the lack of informational accessibility, either through literature or family reports, it is important for the adolescent child to be present in order to gain first-hand, valid information and therefore regaining some control.

“more for my peace of mind that I stay at home”

[Kathleen, T1, line 158]

The emotional need changes as the situation becomes habitual. The practicalities overtake the emotional upset of an uncertain future.

*“I guess you do get used to it...the fear that she's never going to
get better er...goes, and when the fear goes, you can just get
started with stuff”*

[Kathleen, T1, lines 184-186]

The ways in which the participants dealt with their emotional responses differed, some found the outpouring of emotions to be counterproductive to their coping.

“cried, well not like weeping and sobbing, but tearing up. It kinda didn’t help with feeling any better. Just made me feel really, er, bloody awful”

[Paul, T3, lines 156-158]

The acknowledgement of their sorrow and the fears of the family were too much for Paul to contend with, the expressing of emotion shares some links in with *Protector of Others* and *Information and Emotional Response*. The individual’s perception of acceptable emotional feelings and expression impose their own judgments, being alone gives them space where they can let their emotions out. The analysis did raise some interesting gender differences surrounding the acceptable expression of emotions and emotional response.

“I do cry about it”

[Carly, T6, line 353]

The more the young adults have practical experience with the illness the more control they feel they have, thus focusing their energy on issues and tasks as opposed to concentrating on the intangible and unpredictable qualities of emotions.

“I’m not upset really I’m angry”

[Jayne, T7, line 385]

3.4.4.4 *Illness Cycle*

As aforementioned the inconsistency of the illness cycle can feel like a torturous experience for the young adult to have to navigate, the lack of certainty and control being difficult for the young adult to moderate in their daily life.

*“There are times when it can make her really sick, and
sometimes she gets so tired she can’t stay awake much past
7:00. Other times she’s ok though.”*

[Carly, T6, lines 129-132]

The next extract from Kathleen conceptualises the illness in different stages requiring different parts and roles to be fulfilled up until the point where the two sisters can give themselves a social cue that the worse is over by getting out of the house and treating themselves. The concept of their going to McDonalds is symbolic of their feeding their ‘child’ part that had been ignored during the critical part of the illness cycle.

*“we’ll go out to get a McDonalds when mum is starting to come
out the other side, she doesn’t like the smell of cooking and its
kinda of a like a sign to us that we can er, begin to stand down
and like she’s getting better.”*

[Kathleen, T1, lines 533-537]

The linguistic use of the words ‘stand down’ is reminiscent to military terminology potentially being indicative of Kathleen’s feeling that she is at war and battling with trying to cope and manage her parent’s illness.

3.4.4.5 *Roles*

Throughout the transcripts there has been the covert undertone of the young adults having different roles which they need to fulfil. They are acutely aware that their situation is not part of the norm. They are not able to identify with their peers and as such have lost sight of what their role is within their family and society as a whole.

“It’s like I’m living a different life to everyone else”

[Jayne, T7, lines 147-148]

As aforementioned, the young adult tries to emit a carefree persona. During this time, there is the self-imposed felt pressure to relieve the emotional impact of others through pretending to be emotionally sound.

“that’s why I tried to be the happy go lucky daughter”

[Julie, T2, lines 227-228]

The young adults get increasingly more accustomed to having to deal with their parent’s illness. As the illness becomes a part of their life and more embedded into their family unit, they begin to conceptualise their own mortality and destiny. The female participants explicitly state that their future health is something which causes them fear, and that they view their parental situation as prophesising their future. The male participants do not explicitly state that they are fearful of their future health, yet they have health fears which will be examined later in the text.

*“I’m just scared that I’m going to turn into mum, like get poorly
and moody”*

[Carly, T6, lines 439-440]

The confusion of roles could be further understood when not only are the young adults trying to overtly ‘play’ the happy go lucky child, but also the carer, this complicated mix elucidates feelings of being the head of the household and being primary carer.

“It’s like at times, I feel like I’m her mum”

[Carly, T6, line 320-321]

Carly feels very much alone in her plight and in her transformational teenage years. The concept of the young adults feeling like they are the parent is a driving force behind their need to protect others, being synonymous with parental duty.

3.4.4.6 *Protector of Others*

An overt and covert theme of *Protector of Others* has been present throughout the transcripts. The young adults feel a duty to provide a stress free environment as they fear that the family unit could shatter.

*“there were times when I wouldn’t tell dad how bad she was in
case he left us”*

[Carly, T6, lines 292-293]

The young adult feels responsible to protect their younger siblings, being the unconscious transference and counter-transference of undertaking a maternal role and parentification; restricting typical adolescent activities, curbing means of growing up.

*“I know my sister could not take the pressure as well as I
can...er, yeah, that’s another worry about moving away to
University”*

[Kathleen, T1, lines 166-168]

Protecting their parents from the felt emotional distress was a recurrent theme. They attempted to hide their emotional turmoil for the family to be a more harmonious and less stressed environment.

3.4.4.7 *Duties*

Young adults have many different roles and identities, as part of their new life they are required to fulfil duties. The young adults are happy to care for their parent and acknowledge that they have usable knowledge for their future.

*“I suppose I have had to grow up really quickly and take on lots
more responsibility, but I now do feel prepared to take on so
many things.”*

[Carly, T6, lines 537-539]

Tasks offer the young adult a sense of ‘self’, reliability, direction and pride, but in early care-giving these chores induced pressure because of their inexperience. Trying to marry work pressure, parental need and their self imposed pressures of trying to keep stress levels low is a complex task which impacts upon their biopsychosocial and emotional wellbeing.

3.4.4.8 *Unacknowledged Coping through Practical Diversions*

Whilst the female participants acknowledged the physiological and psychological effects of their parental illness, the male participants expressed their unrest through sublimation and dissociative methods. The felt impact and lack of control makes its presence felt through the individual trying to get a sense of future control.

“When I start medical school they will a, I’ll have a better understanding and they will, y, be able to get the proper facts”

[Paul, T3, lines 244-246]

Paul believes that once he has the knowledge of the doctors he will be in a calmed and privileged position which will give him the ability to help his family. He states that he had decided to become a doctor shortly after witnessing his father have an epileptic fit for the first time.

As noted in the theme of *Roles* the female young adults began to conceptualise their mortality by contemplating the genetic factors which could influence their chance of contracting the condition. The male participants did not explicitly state that this was an issue, yet the fear of becoming ill has impacted upon them, even though it was not openly acknowledged.

“I had really good er stamina and str...strength and to keep my body fat down. So I run to make sure I keep my body fat low and that I feel fit. It’s made a huge difference to how I feel. My stamina has got better, I’m running more. It’s good.”

[Jason, T4, lines 36-40]

Jason is adaptively coping and dealing with the impact of his parental illness and fears for his future self through protective health behaviours of increasing his health through diet and exercise.

The analysis suggests that there are many unmet psychosocial and supportive care needs for these young adults, yet it would seem remiss to not mention the positive aspects which the adolescent children have experienced. The participants felt more equipped to take control of practical duties and matured more quickly than their peers. They view their family as important and precious and selflessly take care of them, as they were taken care of when they were children. The preciousness of their family life and security are valued.

3.5 DISCUSSION

3.5.1 Overview of the findings

This study aimed to explore the experiences and unmet needs of young adults who have a parent with a NCD. The findings reported in Chapter Two demonstrated that there was a lack of research examining the unmet psychosocial and supportive care needs of young adults who had a parent with a NCD. Our knowledge on this topic, to date, comes mainly from the psycho-oncology literature. The findings from this study are comparable with this literature, yet there are some differences worthy of discussion.

The themes emerging from this analysis demonstrated that the unmet psychosocial and supportive care needs resulting from having a parent with a NCD were conceptualised by participants and categorised into four super-ordinate themes – two being related to intrapersonal needs (*The Need for Acknowledgement, The Need to be Themselves*), and two related to interpersonal needs (*The Need for Information, Social Need*). These interpersonal and intrapersonal themes are highly interdependent, being symbolic of the differing means through which needs can be met (i.e. the family could provide information and emotional support and access to increased society).

3.5.2 Need for information

The importance of information in helping family adjustment to ill health has been widely reported (Hymovich, 1995). These participants had a universal need for more frequency and/or clarity of information; this supports the previous literature. Research by Arora *et al.*, (2002) suggests that the need for information and the difficulty in accessing it negatively impacts upon

the ill individuals' emotional, functional and social well being; this study supports this. Within this context, information fulfilled different roles, including controlling emotional response and normalising the illness situation. Young adults gained information from different sources in piecemeal fashion as opposed to this being provided by one source in a coherent and complete form. Social barriers (e.g. lack of ability of access to clinicians) prevented the adolescents feeling fully informed; as such they may have placed more confidence in its ability to pacify and control the situation. The adolescent children may have hoped that information could make the situation feel better or have misattributed information as causing emotional calming as opposed to the elapse of time and habituation of the situation.

The participants felt increased internalised pressure at undertaking the caring role, which was not helped by their lack of information and caring experience. The young adults conceptualised that they were disadvantaged due to society and more powerful others (Foucault, 1988) classifying them as not being able, or needing to understand the situation. This impacted upon their feelings of vulnerability and powerlessness at being able to meet their own needs.

In the absence of information from more informed others, these participants gained information from a variety of sources and resources, yet the secrecy with which they cared made accessing information difficult. Research by Agosto and Hughes-Hassel (2005) found that children, aged 14-17 years, preferred friends and family as their sources of information, yet the lack of peer knowledge and parental protection reduced the amount of available information (Kristjanson, *et al.*, 2004). Dina *et al.* (2001) suggests that young adults feel confident and self-assured in accessing the internet in order to gain information specific to their requirements, but this information can often be unreliable (Kortum, Edwards, & Richards-Kortum, 2008). Whilst

information was held as an important unmet need, one participant found that receiving information had a negative impact, echoing parental fears of information being too emotionally loaded for adolescent children to manage (Rosenheim & Reicher, 1985).

3.5.3 Social Need

The analysis suggests that there are a number of anxieties and stressors felt by the young adult within the caring role (Stiffler, Barada, Hosei, & Haase, 2008), and that social support can act as a protective factor (Garmezy, 1991). Different branches of society, from the microsystem through to the macrosystem, can provide specific information to adolescent children about their parent's diagnosis. The way in which society conceptualises the illness and its subsequent severity appears to be a mediating factor in the provision of need and the way the child gains access to peer support and understanding (Bester, 2007; Blumer, 1969).

3.5.3.1 Social Acknowledgment

The illnesses were not deemed by the participant's peers to be life threatening, thus creating a barrier for the adolescent children to get understanding, help, support, and respect (Blumer, 1969; Prinstein & Dodge, 2008). There was the undertone that the young adults required society to recognise the difference in their life as a direct comparison to their peers. There was also the sense that they were powerless without society's help to understand their role and ever changing identity. Research by Thomas *et al* (2003) noted a need for adolescent children's input to be acknowledged by their school and family's clinicians, yet the findings from this study illustrate the varying layers of acknowledgement and its subsequent impact.

The young adults required recognition for who they are, what they do and how this differs from the norm. Their role as carer, and its subsequent emotional and physical hardships, was misinterpreted by their family. This could be a result of parental defences not recognising the impact their illness is having upon their child (Forrest et al., 2006), or due to the adolescent masking its effects (Goffman, 1959). This research further highlights the need to speak to the caregivers directly, no matter what their age or role, as opposed to getting information from third parties (see also Palmer, Wilson-Smith and Hulbert-Williams, *in review*).

3.5.3.2 *Attachment through Social Development*

The microsystem of family and immediate friends has been theorised to be important during adolescence: the family provides instrumental caregivers and friends offer emotional support (La Greca, Auslander, Greco, Spetter, Fisher & Santiago, 1994). The quality of perceived attachments both to family and peers is associated with well-being. Greenberg, Siegel and Leitch, (1983) found that quality of adolescent and parental relationships was a more powerful predictor of well-being than the quality of peer relationships, yet this may be due to the young adults being in an adaptive and supportive family dynamic, thus increasing feelings of worth (Rogers, 1961).

Individuation is an important developmental task which is fluid throughout the lifespan yet is crucial during adolescent development (Erikson, 1950; 1968) and is facilitated within the context of peer relationships (Grotevant, Thorbecke & Meyer, 1982) and developmental separation from the family; this may be hampered when a member has a chronic illness (Daniels, 1990), as the adolescent's parentification acts as a barrier to their self identification (Lewis, Ellison, & Woods, 1985). Disruption of this identity process could impact upon the individual's self concept and

expectations from others thus creating intrapersonal and interpersonal discord (Joubert *et al.*, 2001).

3.5.3.3 *Social Identity and the Need to be Them-Self*

The participants' discourse in this theme surrounded the need to be them-self and in some cases to escape their situation, giving them some respite and time to process their situation. They required support from their peers, yet it appeared that their friends were not as supportive or understanding as they would have liked, whether due to their emotional maturity, or to the young adult not wishing to self disclose to their friends. Access to social support may be mediated by a family code of burying information from outsiders which could cause shame upon the family (Afifi & Olsen, 2005). Social support may also have been hindered by the adolescents putting on the facade that everything was fine by moderating their distress and information need in order to protect family members from upset (Afifi, Olsen & Armstrong, 2005; Goffman, 1953; Petronio, 2002).

3.5.3.4 *Family Dynamics and Trust*

The less supportive the young adult's social network, the less trust they had and the more they internalised. The young adults feel a duty to protect their family unit, including from the uninvited interventions of others who could further disrupt their family life and take the caring role out of their hands (Hindle, 1998), which is not the intention or goal of the young adult (Thomas *et al.*, 2003). The family had a desire to protect one another, with the young adults and parents trying to minimise each other's exposure to increased distress, either through not acknowledging felt pressures or through the monitoring and accessibility of information regarding to the intricacies of the diagnosis and prognosis. Secret keeping (Vangelisti &

Caughlin, 1997) and subject avoidance (Afifi, McManus, Steuber & Coho, 2009) have been found to have an inverse relationship with relationship closeness and satisfaction. The experiences of the young adults in their restricted social voicing of concerns, potentially due to not knowing where to turn, creates a cycle of concealment (Afifi & Olsen, 2005) where individuals are not able to open themselves up for assistance thus remaining stuck in the cycle; this could be conceptualised as the chilling effect (Afifi & Olsen, 2005).

3.5.4 Gender Differences

There were two male and five female participants within this study and as such any gender differences cannot be generalised to the population, however the analysis noted some interesting differences between the two genders.

3.5.4.1 Gender differences and care giving roles

It was noted that the female participants undertook a more active form of caring (Stone, *et al.*, 1987), such as cooking and cleaning. This may down to participant bias as sons had ill fathers, where as daughters, in the main, had ill mothers. It may be that mothers did care-giving tasks as opposed to their sons. Females have interpersonal identities, indicating that they relate themselves to their social situation. This may make them feel more able to under-take a social role than males (Douvan & Adelson, 1966). The female participants found emotional release through talk and emotional expression, yet the male participants stated that this was not a useful technique (Brody, 2000). The males did not find it helpful and did not know what to say to their peer group, but this could be a reflection of their interpersonal development rather than their caregiving role per se (Burlison, 1997; Dindia & Allen, 1992; Douvan & Adelson, 1966).

3.5.4.2 *Gender differences and future fears*

Both males and females began to conceptualise their future health, yet they expressed this in different ways. The females were explicit in their concern for the future, with one individual stating that she had gone for tests to see if she had the same condition as her mother (Buckley, 1977; Hilton & Elfert, 1996; Kennedy & Lloyd-Williams, 2009). Yet a male participant expressed his concern for his future through sublimating his fear by partaking in protective health behaviours. The other male participant gained a sense of control and power through his studying hard in order to train to be a doctor, offering some mental distraction. These are considered to be mature planification defence mechanisms (Conte & Plutchik, 1995).

3.5.5 *Inter-Relating Themes*

Availability of Honest Adult Information and *The Secret Carer* shared some parallels. The young adults' caregiver role was invisible to society, possibly due to their wishing to protect their parent from additional emotional impact (Hindle, 1998). Owing to their lack of power (Foucault, 1988) their ability in gaining access to energy resources such as information (Hobfoll, 1989) was vastly reduced. The secrecy with which they were caring and the changing familial roles impacted upon their condition resources, being their friends (Hobfoll, 1989). The reduced power, microsystem and informed mesosystem (Bonfenbrenner, 1979) lessened the available avenues for accessing informational support specific to their parent's condition, leading them to having to try to make sense of more generic or sensationalised information from unmonitored sources (Oakley, et al., 1995). The reduction in their peer involvement and in feeling marginalised by society left them feeling invisible and alone.

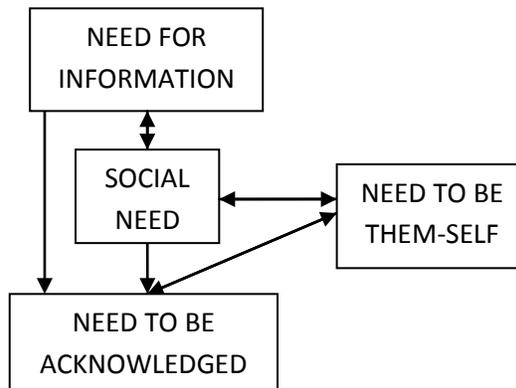
Honest Adult Information and *Protector of Others* shared some similar concepts. The young adult appeared to trust information to treat them like an adult and not sugar-coat the truth. They saw their parents as unreliable for fear that they may be sheltered from bad news. This could be due to interfamily transferences (Leiper & Maltby, 2004), potentially mirroring their actions at protecting their parent from the emotional, social and practical impact of their new found caring role (Kristjanson, et al., 2004).

The interrelating themes of *Desired Information* and *Social Understanding* have the end goals of informing the young adult's social circle as to the parental condition and its impact upon family life. This may help elicit some of the emotional and practical support which they needed to help regulate their emotional discomfort, rejoin the world and feel accepted within their peer group. It is likely that *Protector of Others* and *The Secret Carer* were suppressors in divulging the illness' impact. The access to information would also likely be increased through a larger opportunity of social contact; this then has implications and links to *Need for Acknowledgement*. Had the young adults situation had been acknowledged, their access to information and its subsequent benefits of emotional calming through increased knowledge and practical duties could have been fulfilled (Kennedy & Lloyd-Williams, 2009). This then parallels with *Duties*, where the young adult is better able to fulfil their role if they have information and knowledge to help them complete their tasks. The pressure of the duties would be compounded by the lack of certainty and internalised pressure of the caring role. By having increased access to social support, the adolescents would be more likely to receive information, and practical assistance, which would then, in turn, help with some of their emotional regulation.

The themes were highly interdependent and this reflects the wider literature on unmet needs (see Chapter Two) where fulfilment of one need is frequently reported to have further reaching implications for other needs. This study also demonstrates how needs are multi-directional and interlinking, indicating that the implementation of a resource to fulfil an unmet need could be beneficial to overall wellbeing.

Further multi-directionality of needs is demonstrated in so much that information was required from society, yet this information would be beneficial in informing the young adult's more immediate society. *The Secret Carer* conceptualised the young adult's feelings of invisibility, due to society not recognising their role or situation owing to social perception, which is driven by information, impacting upon the adolescents' emotional state, where in order to try to feel better they looked towards information to aide their coping, yet this was not available as society didn't 'see' them.

Fig 3.1 Showing the directional interlinking of needs



3.5.6 Positive aspects

Despite the barriers and changes in the young adults' circumstances, positive outcomes were noted throughout the transcripts. Young adults felt more able to take on adult responsibility and roles through planning and felt as though they had matured and recognised the value of their family relationships. One participant had decided to become a doctor and was focused on making a difference within society, whilst other participants had taken their future health into their control through having tests and partaking in health-protective behaviours.

3.6 STUDY CRITIQUE AND EVALUATION

This study has been critiqued by using the CASP (2006) for qualitative research, which follows similar guidelines to Yardley (2000). This study asked a research question in which IPA was an appropriate mode of analysis and has included detailed procedural and ethical information.

Participant rationale and choice was explained, recruitment was through self-selected sample, and as such participant data may have come from individuals who had strong opinions. The role of the researcher and reflexivity in the choice of questions has been conceptualised in Chapter

One. In order to reduce researcher bias the transcripts were validated to create a joint framework, which was confirmed by the supervisory team. Transparency was ensured as tables were constructed of exemplar quotes. The findings have been discussed comprehensively and with reference to existing literature and the thesis' theoretical framework. Findings which are unique to this study were noted and translated into how they could be beneficial to counselling psychology practice. Future research ideas are conceptualised with the view of being beneficial in directing future research.

3.7 IMPLICATIONS FOR COUNSELLING PSYCHOLOGY PRACTICE

This research indicates that the young adults have a plethora of emotional reactions to having a parent with a NCD. Social barriers to information hamper adolescent's from receiving information which may be useful to them, and as such they are left feeling unsettled as they feel that their stable family unit has become threatened (Forrest, et al., 2006). Counselling psychologists work in a variety of setting and as such are readily available to provide a safe therapeutic space where clients can explore the feelings surrounding their new role, other family members, and the potential loss of their 'child' self (Perls, 1969). This would be beneficial in reducing distress and improving quality of life (Friedlander, Reid, Shupak, & Cribbie, 2007). Counselling psychologists could help to inform change through having access to increased knowledge of the impact of unmet needs. The development of age appropriate information leaflets within both primary and secondary care settings, and in offering group or individual sessions to young adults who have a parent with a NCD as a standard part of clinical practice, the adolescents would have more opportunity of being able to take some control and gain power.

3.8 CONCLUSION

Young adults who have a parent with a chronic illness have a variety of unmet needs. The role of society is an important one in fulfilling many of these unmet needs. Peer and parental support should not be underestimated owing to adolescence being a time of transition, with the attachment system requiring differing interpersonal introjections in order to help regulate emotions and develop a robust sense of self.

Further research into this subject area may be of benefit to determine interventions to assist young adults who have a parent with a chronic illness. In order to develop such interventions however, we need to understand prevalence and consequences of specific unmet needs.

Quantitative approaches are perhaps more appropriate here as they can identify associations between unmet needs, affective state and quality of life outcomes. This additional knowledge has benefit to psychological practitioners as it provides evidence of how unmet needs affect well-being and could inform future psychosocial and supportive care interventions, which could be readily justified as adhering to evidenced based practice.

CHAPTER THREE

ABSTRACT

This study used a revised measure of unmet needs, namely the OCINI to quantitatively investigate the unmet needs of 107 young adults who have a parent with a non-communicable disease (NCD). The OCINI had good internal reliability; analysis indicated that adolescents have a variety of unmet needs, and that unmet needs were co-dependent and associated with outcome variables of depression, anxiety, stress and quality of life. Findings are comparable to adolescent unmet needs when they have a parent with cancer. Regression analysis indicates that certain needs are predictors of criterion variables. The models produced from the regression analysis would help inform counselling psychologists in providing psychological interventions, assessments, and needs-based programmes.

Further research using longitudinal data would be beneficial in determining cause and effect, this would help inform to offer valuable insight in predictor variables, thus helping to put appropriate interventions into place before well-being was too detrimentally affected. Due to counselling psychologists working within primary and secondary care, it is suggested that they are well placed to conduct such research.

KEYWORDS: unmet needs, non-communicable disease, adolescent children, multiple regression.

CHAPTER FOUR
YOUNG ADULTS WHO HAVE A PARENT WITH A NON-COMMUNICABLE
DISEASE:
THE RELATIONSHIP BETWEEN UNMET PSYCHOSOCIAL
AND SUPPORTIVE CARE NEEDS, QUALITY OF LIFE,
ANXIETY, DEPRESSION, AND STRESS

4.1 INTRODUCTION

4.1.1 Background

Chapters one and two outlined the importance of investigating unmet psychosocial and supportive care needs of adolescent children who have an ill parent. Research with adult caregivers and spouses suggests that unmet needs are present in 40-70% of adult carers (Moser, et al., 1992; Soothill et al., 2001) and adolescents have less opportunity to access resources to meet their needs due to their lack of social power (Foucault, 1988). The literature summarised in Chapter Two demonstrated a lack of published literature about the lived experience of young adults who have a parent with a NCD. The conclusions suggested that adolescent children had psychosocial and supportive care needs relating to accessing *information, practical duties*, having time for *recreation*, understanding *emotions*, gaining *acknowledgement and recognition* that their life was different from that of a 'normal' teenager.

The analysis presented in Chapter Three built upon this knowledge and highlighted the plethora of different interlinking unmet needs which adolescents may experience during parental illness. The emergent themes suggested that these needs may impact upon the

adolescent's affective state and adaptive coping, suggesting the need for further research which is best suited for a quantitative methodology by looking at associations between unmet needs, affective state and quality of life.

4.1.2 The Value of Quantitative Research

Qualitative research offers an idiographic understanding of the individual's phenomenological and subjective experience and develops theory inductively but results cannot be generalised to wider populations. Quantitative research, as an alternative, uses a positivistic approach; aiming to be objective and systematic, producing numerical data under controlled conditions (Duffy, 1985) to quantify, measure phenomena, and to produce generalizable findings examining cause and effect relationships (Burns & Grove, 1987). As opposed to qualitative methodologies, quantitative research uses deductive methods of knowledge attainment (Duffy, 1985).

This study seeks to use quantitative methods to investigate the associations between unmet psychosocial and supportive care needs with self-reported quality of life, anxiety, stress and depression in young adults who have a parent with a NCD. Together with findings presented earlier in this thesis, this information will provide a holistic overview of the not only the lived experience of adolescent children's unmet psychosocial and support care needs, but also the extent of their potential impact on well-being. This can be used to inform future needs-based interventions for this population (Watson *et al*, 2012).

4.1.3 Study Question, Aims and Hypotheses

Due to a lack of published research, it is impossible to know whether adolescent unmet needs vary between NCD, cancer, and psychological problems or if unmet needs are 'standard' when adolescents have an ill parent; the cancer literature provides a reasonable baseline for investigation of the association of adolescent children's unmet needs with depression, anxiety and stress. For example, Patterson *et al* (2010) reported positive associations between unmet need and affective state with adolescent children who had a parent with cancer. This gives rise to the question explored in this study:

Question 3: What is the relationship between adolescent children's unmet psychosocial and supportive care needs, quality of life, anxiety, depression, and stress scores?

This study aims to determine: (i) the current unmet psychosocial and supportive care needs of young adults who have a parent with a NCD, and (ii) the association between these unmet needs with affective state and quality of life outcome measures. The following hypotheses will be tested:

Hypothesis one: Young adults will have a variety of unmet needs.

Hypothesis two: Young adult's quality of life and affective state will be associated with the individual's unmet needs.

Hypothesis three: Unmet needs will predict an individual's affective state and quality of life.

Patterson *et al's* (2010) research used the only specifically designed measure of unmet needs relevant to adolescents who have a parent with cancer (the Offspring Cancer

Needs Inventory, OCNI; Patterson, *et al.*, 2010). For the purposes of this research, special permission was sought from the authors to create a modified, more generalised version of the measure. To date, this is the only study that has been granted permission to use the OCNI in this way. This revised version will be referred to as the OCINI (Offspring Chronic Illness Needs Inventory).

4.1.3.1 *Development of the OCNI and OCINI revision*

Structured questionnaires are useful tools for collecting and recording multiple records of information about an issue which can be statistically analysed. Patterson *et al* (2010) used qualitative methods to develop items for potential inclusion in their unmet needs scale. The OCNI was piloted with 116 young adults (77 daughters, 39 sons), aged between 12 and 24 years. They were recruited through an existing Canteen Research database. Ninety percent of the participants lived with their parent who had received a cancer diagnosis within the past five years.

The young adults answered questions on the OCNI about their current needs and their more enduring needs over the past twelve months, these latter needs were defined as unmet needs. The participant's mental health scores were determined by the Depression, Anxiety and Stress Scale, short version (DASS-21) for individuals aged 18-24, and the Strengths and Difficulties Questionnaire (SDQ) for individuals aged 12-17 years. The OCNI and 'mental health' screening tools were used to determine frequency of needs and the association of needs with affective state and psychological well-being.

The findings showed that 97.4% of the adolescents had at least one current need which was yet to be met. 90% of the participants had 10 or more current needs, yet 47% of

these individuals had had some of their needs met. This may be due to the sample being part of a supportive group where they can link in with other individuals in a similar situation (Northouse & Swain, 1987). Approximately 25% reported having 50 or more current needs. On average participants had 36.2 needs (SD=17.44, range=0–66). 87% of the sample reported having at least one unmet need, being a need which was enduring for a 12 month period. Forty three percent had 10 or more unmet needs, and just under a quarter had 20 or more unmet needs. On average, participants reported 12.82 unmet needs (SD=13.33, range=0–54). Further analysis showed a positive relationship between the number of unmet needs and mental health scores as measured by the SDQ for participants aged 12-17 (n=98) ($r=0.33$, $p<0.001$). Participants aged 18-24, were also noted as having positive associations between affective state as measured by the DASS-21 and unmet needs; stress ($r=0.56$, $p<0.01$), anxiety ($r=0.66$, $p<0.01$), and depression ($r=0.77$, $p<0.001$). This is the only piece of quantitative research which gets information from the adolescent about their unmet needs and their association with affective state.

This study will modify the OCNI by interchanging the word cancer for chronic illness (i.e. *I need information about my parent's cancer and its impact on their life*, to, *I need information about my parent's illness and its impact upon their life*), thus adapting it into the Offspring Chronic Illness Needs Inventory (OCINI). Basic psychometric analysis will determine if the scale is valid within this population prior to use of inferential statistics to test the study hypotheses.

4.2 METHOD

4.2.1 *Study Design*

This study will use a cross sectional sample of adolescent children who have a parent with a NCD. Cross sectional studies are advantageous as they give researchers a snap shot in time; it will help to determine the prevalence of unmet needs in adolescent children who have a parent with a NCD. Cross sectional designs are also useful in exploring associations that might benefit from later research using longitudinal cohort designs to investigate cause and effect relationships.

4.2.2 *Participants*

4.2.2.1 *Sample size calculation*

Sample size calculations ensure that statistical analyses are adequately powered to detect true variable effects whilst simultaneously minimising the chance of statistical error (Field, 2009). In particular, power calculations help to minimise Type II errors (when significant effects are wrongly concluded; Rosnow & Rosenthal, 1989) by determining required sample size based on expected effect size and pre-determined alpha level (Rossi, 1990).

Sample size calculations are informed by the type of statistical test required by study hypotheses, in this case, multiple regression analyses. There are many different ‘rule of thumb’ estimates for adequate sample sizes within regression models which can range from 5:1 to 25:1 ratios of participants to predictor variable (Green, 1991; Tabachnick & Fidell, 2000). Green (1991) provides an alternative method of sample

size calculation (based on expected effect size) which is considered to be more robust than other 'rule of thumb' methods.

Expected effect sizes are based on the Patterson *et al* (2010) study which reported r values in the range of 0.33-0.77 (medium to large effect sizes; Cohen, 1988). The number of predictor variables which would be entered into regression models was unknown until the analysis began and significant associations were found, however it was estimated that this would be between 15 and 20 given the measures selected. Under these circumstance, Green's rule of thumb (1991) suggested that 138-156 participants were required power analysis to 80% to detect medium effects ($R^2=0.13$). Therefore this study will aim to recruit in excess of 138 participants.

4.2.2.2 Participant inclusion and exclusion criteria

Participants needed to:

- Have a parent who had been diagnosed as having a chronic illness by a medical professional (chronic illness was used as opposed to NCD as it is more commonly understood).
- Live with that parent, or spend at least two nights a week with them.
- Be aged between 17 and 24 – this was a condition of the university ethics committee.
- Have not taken part in the IPA study in Chapter Three.

4.2.2.3 Procedure of participant recruitment

Owing to this research being time limited due to Practitioner Doctorate in Counselling Psychology regulations, it was deemed that it would be time consuming to receive NHS ethics. Instead, the researcher applied for university ethical approval for participants to be recruited from private organisations (e.g. Private health providers, Universities) and charities who worked with ‘young carers’ across the West Midlands and Wales region. Key personnel in each institution were provided with questionnaire packs (consisting of the quantitative measures, demographic detail form, consent form, information sheet, and debriefing sheet; Appendix 4.1) for distribution.

The young adults collected these packs directly from the charity or health care centre, and either filled it in straight away or took it home and returned it at a later date. Boxes for the forms were located within the organisations where individuals could securely and confidentially return them. The questionnaires were placed within an envelope and the consent forms were added to the box separately. The charities and private health centres then returned the completed questionnaires and consent forms to the researcher in the provided stamped self-addressed envelopes. University students were also recruited; these were made aware of the study through a poster being placed within the main campus. Individuals were able to contact the researcher through email in order to receive the questionnaires, they were returned either in person at a time of mutual convenience or were given to the psychology secretary to keep safe for the researcher to collect.

4.2.2.4 *Participant numbers and return rates*

Of the 170 questionnaires distributed, 107 (63%) were returned. Participants included 73 females (mean age 18.22 (SD 1.16)) and 34 males (mean age 18.65 (SD 1.25)). The

inclusion criteria specified that participants needed to have a parent who has been diagnosed as having a chronic illness by a medical professional. The parental illness groups are illustrated in table 4.1. Although the number of participants recruited was less than that aimed for (based on sample size calculation), later confirmatory testing based on achieved, rather than expected, effect sizes confirmed the analyses to be sufficiently powered (tests conducted using G*Power v3.1).

4.2.3 Measures

4.2.3.1 Offspring Chronic Illness Needs Instrument (OCINI).

As described in section 4.1.3.1, this is a modified version of the 46 item Offspring Cancer Needs Instrument (OCNI, Patterson, *et al*, 2010). The questionnaire is a Likert scale rated from 1-4, where 1 indicates ‘No Need’ (I don’t have any need for help with this issue) and 4 indicating ‘Strong Need’ (I have a strong need for help with this issue). Items group onto seven sub-scales. The Cronbach’s α for the OCINI subscales in this study are (in parenthesis): Information (.86), Family Issues (.67), Practical Assistance (.91), Time Out and Recreation (.84), Dealing with Feelings (.94), Support from my Friends (.83), and Support from other Young People (.73). These reliabilities adhere to Kline’s (1999) recommendations that α should be at least 0.70, with the exception to Family Issues which falls short by 0.03. The Cronbach’s alpha are very similar to those found by Patterson, *et al* (2010) with the OCNI.

4.2.3.2 Depression Anxiety and Stress Scale (21 item short version) (DASS-21) (Henry & Crawford, 2005).

The DASS-21 is a Likert scale made up of 21 items, this has been reduced from the Lovibond and Lovibond's (1995) 42 item DASS self reported Likert scale of depression, anxiety and stress (DASS). The Cronbach's α of the DASS-21 within this chapter were .88 for depression, .82 for anxiety, .90 for stress and .93 for total scale which all fall within Kline's (1999) parameters.

4.2.3.3 *Adult-Carers Quality of Life Scale (AC-QoL) (Elwick, Joseph, Becker & Becker, 2010)*

The AC-QoL is a newly devised quantitative measure of quality of life for unpaid, adult carers. The population utilised for the piloting of the scale were aged 19-93. The questionnaire is a Likert scale with responses ranging from 'Never' to 'Always'. There are 8 sub-scales, being Support for Caring, Caring Choice, Caring Stress, Money Matters, Personal Growth, Sense of Value, Ability to Care, Carer Satisfaction. Each sub-scale has 5 items, with the entire measure being made up from 40 questions. The scale can be used by adding the subscales together to give a total score for quality of life. The total score was used within the analysis, and had a Cronbach's α of 0.89. As the scale is new there were no published validity levels, yet communication with the authors also confirmed that the scale was within acceptable levels of validity. This questionnaire was chosen as it was specifically for informal carers. The age range which was intended for the scale was slightly outside of the participant age range, yet the age range of 19-93 suggested that it had a large range and this research was hopeful in getting a larger range of young adult children, yet this did not happen.

4.2.3.4 *Demographics*

The participants were asked for demographic data, this was mainly quantitative, nominal data. Questions included demographic details such as: *participant age and gender*. Their ethnic orientation was collected owing to research indicating that *ethnicity* can have a bearing upon attachment (Doherty, Hatfield, Thompson, & Choo, 1994), and that attachment could be an influencing factor in how an individual copes with the parental illness experience. Details about the *parental illness* were also collect, including the type of illness, who diagnosed it, how long the parent had been ill, and which parent received the diagnosis. Parental gender may have a bearing upon the caring role of family members. Women are disproportionately more likely to care than men (Stone, *et al.*, 1987). If the mother were ill, family members may have to pick up the extra work, where as if the father were ill, the mother may undertake more caregiver duties. The young adults' *living arrangements* were also collected in order to get an estimate of how long the adolescent was in the family environment. Due to the research looking at affective state the young adults' current and past depression status was also recorded.

4.2.4 Data Analysis

Initial descriptive statistics on participant data were collected to provide a sample description. The data were screened to determine whether parametric tests could be appropriately used. In all cases, data met parametric testing assumptions. Analyses were conducted as follows to address each hypothesis.

Hypothesis one: Young adults will have a variety of needs.

Each item from the OCINI had its high and moderate need frequency calculated to determine the rank order of current needs which young adults have not had met. Percentages of participant's high, moderate, low and no needs were calculated to highlight prevalence of current needs which had not been met.

Hypothesis two: Young adult's quality of life and affective state will be associated with the individual's unmet needs.

Pearson's correlation analysis were performed between all predictor variables (OCINI subscales and demographic items) and outcome variables (anxiety, depression, stress, and total quality of life) to determine which factors were significantly associated ($p < .05$).

Hypothesis three: Unmet needs will predict an individual's affective state and quality of life.

Four multiple regressions (forced entry) were used to analyse hypothesis three as they show how much an independent variable can predict the dependent variable when remaining variables are fixed and controlled for. To reduce the number of predictor variables entered (and, therefore, to better power analyses) only those predictor variables which indicated a significant correlation with outcome variables (in the testing of hypothesis two) were used. Four multiple regression models were tested, each measuring one of the four outcome (depression, anxiety, stress, quality of life).

Each regression model consisted of three blocks. Block one included participant demographic variables (*gender of participant, age of participant, type of illness*, and

duration of the illness). Block two was used to control for the confounding effects of the remaining outcome variables and so in each model contained three out of four of *stress*, *anxiety*, *depression* or total *quality of life*. Block three contained the seven OCINI subscales of need for: *information*, *peer support*, *family support*, *practical support*, *recreation*, *dealing with feelings*, *support from other young adults*.

Standardised Beta and zero-order, part and partial correlations were used to determine the predictive power of the variables within each model. The models produced high zero-order and low part correlations. This means that variables on their own could be a good predictor of the outcome, yet in the presence of the other variables within the model, the variables made a very small unique contribution to the amount of variance explained. Almost all of the predictive powers attributable to these variables were shared with the other variables within the model.

Step-wise regressions were discounted due to inclusion being mathematically led, potentially making them biased as they are based upon the same data (Osborne, 2000), thus affecting the p-value's interpretation. Hierarchical regression was also discounted as variables should be entered based upon their proximity to the outcome variable and causality (Tabachnick & Fidell, 2001). Literature currently does not offer a good enough rationale as to inclusion order.

Outliers can skew data due to it not being normally distributed. Multivariate outliers were found using Mahalanobis distance. As a means of detecting outliers, Tabachnick and Fidell (2001), suggest using the Chi-Square critical values table (criterion of $\chi^2 = .001$) with degrees of freedom being equal to the number of independent variables, not

following the normal convention of degrees of freedom equaling the number of independent variables minus one. Any variables outside of this critical value were excluded from the analysis. Using a $p < 0.001$ criterion ($\chi^2 (14df) = 36.12$) for values of Mahalanobis' distance, two multivariate outliers were detected and removed. A multiple regression was therefore applied with all remaining participants ($n=105$).

4.3 FINDINGS

The data were entered into SPSS 16.0 and analysed (appendix 4.2) in order to test the three hypotheses that this chapter set out to investigate.

4.3.1 Hypothesis One

It was hypothesised that young adults would report a variety of needs which are currently not being met by society or the caring professionals. Descriptive statistics from participant demographics (table 4.1) show that information was more readily given to adolescent children who had a parent with a previous medical history of stroke or epilepsy. These groups received far more information than the other illness sub groups, yet of these two groups only the epilepsy group had access to external practical support, due to the difference in participant numbers between these groups, statistical analysis was not possible (Field, 2009).

Table 4.1 Showing ill parent demographic data and percentage of young adults who had access to information and external practical support systems

Illness type	Number of participants (n=107)	Mean (SD) Time parent has been ill (months)		Young adults received info	Young adults access to external practical support
		Father (n=37)	Mother (n=70)	%	%
Cerebral Vascular Accident (Stroke)	6	n=3 8.67 (1.16)	n=3 9.00 (1.73)	66.66	0
Epilepsy	13	n=2 10.00 (2.83)	n=11 8.64 (2.62)	53.85	18.18
Arthritis	13	n=6 10.50 (1.38)	n=7 9.86 (2.12)	38.46	7.69
MS	14	n=4 10.25 (2.06)	n=10 10.30 (2.71)	35.71	0
Diabetes	19	n=7 15.71 (10.63)	n=12 14.08 (11.34)	31.58	15.79
Chronic Fatigue Syndrome / Myalgic Encephalopathy	22	n=8 13.75 (10.67)	n=14 13.14 (5.59)	13.64	10
Asthma/Acute Respiratory Distress Syndrome	20	n=7 10.43 (2.07)	n=13 21.85 (21.56)	10	0

Needs were further explored by ranking items on the OCINI (table 4.2) based upon their ranking with their individual subscale and the overall scale. The top five ranked needs for the entire scale are as follows. These were shared between *support from friends*, *family issues*, *information*, and *dealing with feelings* subscales.

(1) The highest need was to have *support from friends*,

(2) Joint ranked second need was *to feel that my parents were open with me regarding my parent's illness* and *to be informed about my parent's condition – good or bad*, third ranked need was *to be able to express how I feel about my parent's illness without worrying about upsetting people*.

(3) The fourth ranked need on the OCINI was *to be informed about what is involved in my parent's illness*, and the fifth highest ranked need was *to help dealing with feelings of sadness about my parent's illness*.

The three lowest ranking questions for the entire scale, indicating the lowest number of unmet needs were item numbers

(44) *Need to be linked in with a social support network with others sharing a similar experience*

(45) *Assistance in developing my independence*, and

(46) *Assistance in dealing with the changes in my relationship with my parent*.

Table 4.2 Showing frequencies of high and moderate need of the OCINI, ranked subscales and overall scale ranked questions.

OCINI QUESTIONS		Rank	Overall	f	High	Moderate	Low	No
I currently need...		within	Rank	Reported	Need	Need	Need	Need
		subset	<i>b</i>	Needs	%	%	%	%
		<i>a</i>		(n=107)				
Support from Friends								
Q40	support from my friends	1	1	100	44.9	48.6	6.5	0
Q38	my friends to understand what I am going through	2	7	84	5.6	72.9	19.6	1.9
Q41	my friends to feel comfortable talking to me about my experience with my parent's chronic illness	3	10	78	12.1	60.7	26.2	0.9
Q39	to know how to talk to my friends about my experience with my parent's chronic illness	4	14	71	5.6	60.7	33.6	0
Family Issues								
Q12	to feel that my parents were open with me regarding my parent's illness	1	2	96	18.7	71	8.4	1.9
Q11	to feel I can openly talk with my family about my parent's illness	2	12	76	8.4	62.6	29	0
Q10	to feel that I have support from my family regarding my parent's illness	3	14	71	5.6	60.7	33.6	0
Q13	to know how to behave around my parent who has a chronic illness	4	24	58	3.7	50.5	21.5	24.3

OCINI QUESTIONS		Rank	Overall	f	High	Moderate	Low	No
I currently need...		within	Rank	Reported	Need	Need	Need	Need
		subset	<i>b</i>	Needs				
		<i>a</i>		(n=107)	%	%	%	%
Informational Needs								
Q2	to be informed about my parents condition – good or bad	1	2	96	43	46.7	10.3	0
Q1	to be informed about what is involved in my parent’s illness	2	4	88	5.6	76.6	17.8	0
Q9	information about what to do if I notice a particular side effect or symptom in my parent who has a chronic illness	3	6	85	31.8	47.7	20.6	0
Q7	information about the side-effects of my parent’s treatment	4	8	82	21.5	55.1	22.4	0.9
Q3	to get information about my parent’s illness in a way I can understand	4	8	82	14	62.6	23.4	0
Q4	to be spoken to by a Health Care Professional in a way that I can understand	5	9	81	26.2	49.5	24.3	0
Q5	information about my parent’s illness and its impact upon their life	6	17	67	19.6	43	37.4	0
Q6	information about the chances of my parent’s recovery	7	19	65	16.8	43.9	39.3	0
Q8	information about what happens after my parent comes home after having treatment	8	23	61	12.1	44.9	39.3	3.7
Dealing with Feelings								
Q29	to be able to express how I feel about my parent’s illness without worrying about upsetting people	1	3	93	47.7	39.3	13.1	0
Q27	to help dealing with feelings of sadness about my parent’s illness	2	5	87	0	81.3	17.8	0.9

OCINI QUESTIONS		Rank	Overall	f	High	Moderate	Low	No
I currently need...		within	Rank	Reported	Need	Need	Need	Need
		subset	<i>b</i>	Needs	%	%	%	%
		<i>a</i>		(n=107)	%	%	%	%
Dealing with Feelings cont...								
Q26	help dealing with feelings of anxiety and feeling scared about my parent's illness	3	6	85	5.6	73.8	20.6	0
Q25	to learn ways of coping with the added stress placed upon my family	4	9	81	5.6	70.1	24.3	0
Q30	to have someone close to discuss my feelings about my parent's illness	5	13	74	6.5	62.6	29.9	0.9
Q35	help with feelings that my parent may not get better	6	18	66	0	61.7	27.1	11.2
Q34	help dealing with feelings of frustration and anger related to my parent's illness	7	20	64	0.9	58.9	31.8	8.4
Q33	help dealing with negative changes in my self esteem as a result of my parent's illness	8	21	63	0	58.9	21.5	19.6
Q31	to talk to a counsellor/psychologist/social worker	9	23	61	1.9	55.1	27.1	15.9
Q37	information about the different feelings I might have because of my parent's illness	10	26	56	5.6	46.7	36.4	19.6
Q28	help dealing with feelings of guilt related to my parent's illness	11	27	54	6.5	43.9	36.4	11.2
Q32	help dealing with other people's reactions regarding my parent's illness	12	29	47	0	43.9	39.3	23.4
Q36	assistance in dealing with the changes in my relationship with my parent	13	30	40	5.6	31.8	39.3	23.4

OCINI QUESTIONS		Rank within subset <i>a</i>	Overall Rank <i>b</i>	f Reported Needs (n=107)	High Need %	Moderate Need %	Low Need %	No Need %
I currently need...								
Time-out and Recreation								
Q21	to be involved in activities that distract me from the way my parent's illness makes me feel	1	8	82	3.7	72.9	17.3	5.6
Q24	to spend more time with friends	2	11	77	1.9	70.1	27.1	0.9
Q20	to be able to have fun	3	12	75	0	70.1	29	0.9
Q22	time out from the extra duties that I have taken on at home	4	14	71	6.5	59.8	26.2	7.5
Q23	to feel like a normal young person which it seems I've lost as a result of my parent's illness	5	21	63	0	58.9	33.6	7.5
Practical Assistance								
Q18	assistance with jobs and chores around the house	1	15	70	6.5	58.9	20.6	14
Q14	help to concentrate upon tasks at school, university, college or work	1	15	70	0	65.4	23.4	11.2
Q16	access to information about support services available to me	2	22	62	6.5	51.4	28	14
Q15	my teachers/boss to understand my situation and be more flexible	3	23	61	4.7	52.3	31.8	11.2
Q17	assistance with looking after my parent	4	25	57	4.7	48.6	30.8	15.9
Q19	assistance with developing my independence	5	31	31	2.8	26.2	48.6	22.4

OCINI QUESTIONS		Rank within subset <i>a</i>	Overall Rank <i>b</i>	f Reported Needs (n=107)	High Need %	Moderate Need %	Low Need %	No Need %
I currently need...								
Support from other Young Adults								
Q43	to talk to someone my own age who has been through a similar experience with chronic illness	1	16	68	0	63.6	35.5	0.9
Q42	the opportunity to spend time with other young people affected by their parent's chronic illness	2	19	65	0	60.7	39.3	0
Q46	to be able to learn from other young people who have been through a similar experience with chronic illness	3	23	61	0	57	43	0
Q45	to feel supported by peers who have a similar experience with chronic illness	4	28	52	0	48.6	51.4	0
Q44	to be linked in with a social support network with others sharing a similar experience	5	32	26	0	24.3	72	3.7

a – Rank, based upon frequency of moderate and high needs for each item within each subscale

b – Rank, based upon frequency of moderate and high needs for each item within the scale

4.3.2 Hypothesis Two

It was hypothesised that there would be a relationship between young adult's quality of life, affective state, and unmet needs. A correlation analysis was used to explore association between unmet needs and outcome variables (table 4.3). The analysis demonstrates high degrees of significant positive co-variance ($p < .01$; 2-tailed) amongst all OCINI subscales, between OCINI subscales, affective state and quality of life scores. Effect sizes were, in the main, consistently high between all of the variables. The need for support from other young people had significant associations yet a lower effect size; this, once again may have been due to participants being recruited through organisations geared at assisting families.

High correlations of approximately .8 were noted between the DASS-21 subscales. A result of one would indicate a perfect relationship with no variance, these high associations of .8 may be indicative that the same variables are being measured. There were positive high significant correlations between the OCINI subscales. The three highest OCINI subscale correlations were between *Timeout* and *Practical Assistance* ($r = .858$, $p < .01$, 2-tailed) and *Dealing with Feelings* ($r = .840$, $p < .01$, 2-tailed), and *Dealing with Feelings* with *Practical Assistance* ($r = .838$, $p < .01$, 2-tailed). An inverse relationship was noted between having needs and quality of life score, indicating that needs have a negative effect upon an individual's quality of life.

Table 4.3 Correlation matrix for OCINI subscales, depression, anxiety, stress, and quality of life.

	Dep'n	Anxiety	Stress	Quality of Life	OCINI Info	OCINI Family	OCINI Practical	OCINI Timeout	OCINI Feeling	OCINI Friends	OCINI Other Young Adults
Dep'n	-	-	-	-	-	-	-	-	-	-	-
Anxiety	.814**	-	-	-	-	-	-	-	-	-	-
Stress	.832**	.798**	-	-	-	-	-	-	-	-	-
Quality of Life	-.750**	-.642**	-.771**	-	-	-	-	-	-	-	-
OCINI Info	.749**	.635**	.766**	-.852**	-	-	-	-	-	-	-
OCINI Family	.651**	.598**	.600**	-.790**	.772**	-	-	-	-	-	-
OCINI Pract.	.717**	.673**	.762**	-.747**	.795**	.655**	-	-	-	-	-
OCINI T/out	.722**	.591**	.773**	-.629**	.700**	.514**	.858**	-	-	-	-
OCINI Feeling	.732**	.652**	.706**	-.690**	.680**	.601**	.838**	.840**	-	-	-
OCINI Friends	.591**	.473**	.499**	-.572**	.509**	.452**	.649**	.647**	.762**	-	-
OCINI YA	.400**	.358**	.495**	-.370**	.428**	.321**	.515**	.583**	.647**	.403**	-

** = p < 0.01 (2-tailed)

4.3.3 Hypothesis Three

It was hypothesised that unmet needs will have predictive power in an individual's affective state and quality of life. Analysis set out to determine which predictor variables contributed to the variance in outcome scores. Predictors were entered in three blocks. Tables show data from stage three of the analysis, as this demonstrates the predictive power and relationship direction of all of the variables from the final stage of the model which shows that different OCINI subscales shared diverse associations with the outcome criterions.

4.3.3.1 Depression

The Durbin Watson Statistic for auto correlation was 2.185, indicating independence of the residuals. Normality and homogeneity of variance were not violated.

Model one, containing the demographic variables, accounted for 9.7% of variance in depression $R=.363$ ($F(4,100) = 3.786$, $p < .01$). Model two contained outcome variables of anxiety, stress and quality of life. The model had a r^2 change = .670, and accounted for 78.8% of the total variance $R=.896$ ($F(7,97) = 56.120$, $p < .001$). Block three, contained the final model of the seven OCINI subscales. The OCINI variables contributed a significant r^2 change of .037, and the entire model accounted for 81.4% of the total variance, $r = .916$ ($F(14,90) = 33.578$, $p < .01$).

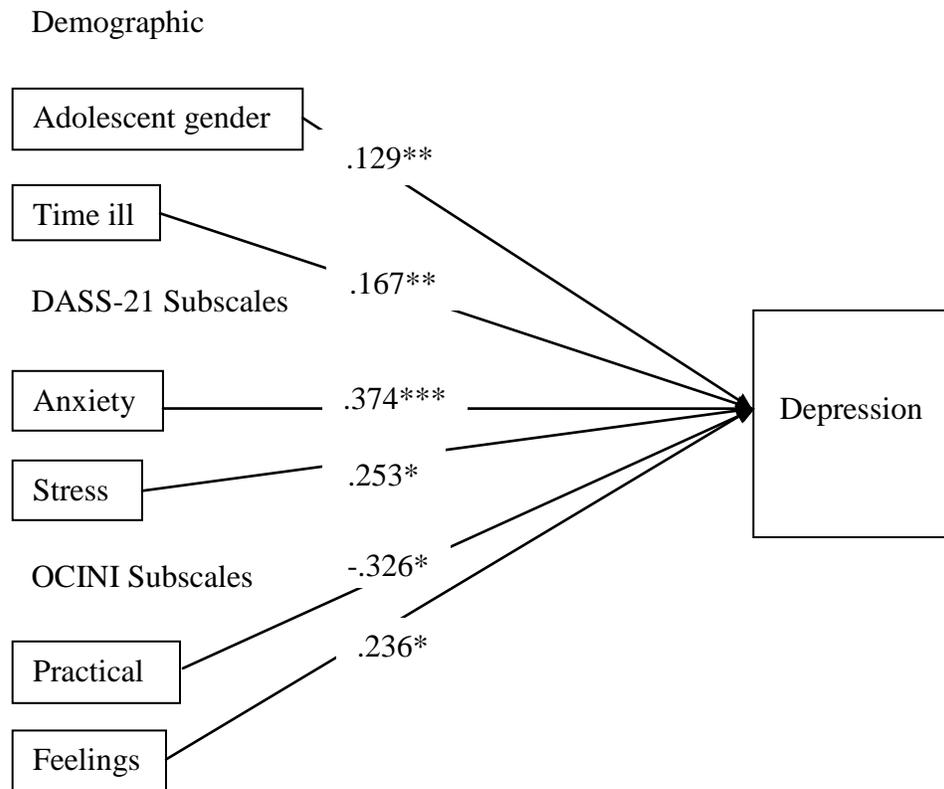
Table 4.4 Showing Beta, Standardised Beta Weights, Significance, Zero, Part and Partial Correlations for Depression

Variables	B	Beta	t	p	Zero order	Semi partial	Part
Anxiety	.470	.374	4.062	.000	.700	.821	.394
OCINI Practical	-.377	-.326	-2.496	.014	.732	-.254	-.105
Stress	.276	.253	2.169	.033	.833	.223	.092
OCINI Feel	.172	.236	2.009	.048	.720	.207	.085
OCINI Info	.227	.208	1.779	.079	.734	.184	.075
OCINI Timeout	.341	.175	1.566	.121	.711	.163	.066
QoL	-.075	-.169	-1.581	.117	-.748	-.164	-.067
Time ill	.102	.167	2.978	.004	-.327	.300	.126
Adolescent gender	1.245	.129	2.699	.008	-.137	.264	.114
OCINI Friend	.228	.097	1.357	.178	.593	.142	.057
OCINI Sup young adults	-.210	-.080	-1.304	.195	.380	-.136	-.055
Type of parental illness	-.147	-.062	-1.306	.195	-.016	-.136	-.055
OCINI Family	.115	.046	.586	.560	.631	.062	.025
Adolescent Age	.092	.024	.536	.593	.076	.056	.023

Table 4.4 shows the relationship direction, beta, standardised Beta weights, part, partial and zero-order correlation. The analysis of this data indicates that significant variables have stronger zero-order correlation with depression than the part and partial correlation; indicating a variance in the prediction of depression when the other variables are present.

Figure 4.1 illustrates the direction of the significant predictors and standardised Beta weights of the depression model.

Fig 4.1 Depression Model



Key = * p<.05; ** p<.01; *** p<.001

The model indicates that daughters were most depressed. Anxiety and stress were positively associated with depression. As the need for expressing emotions increases, so does the adolescent's negative affective state. As the young adults need for practical assistance increased, the individual's depression score decreased.

4.3.3.2 *Anxiety*

The Durbin Watson Statistic for auto correlation was 1.666, being within permitted parameters for the independence of the residuals. Normality and homogeneity of variance were not violated.

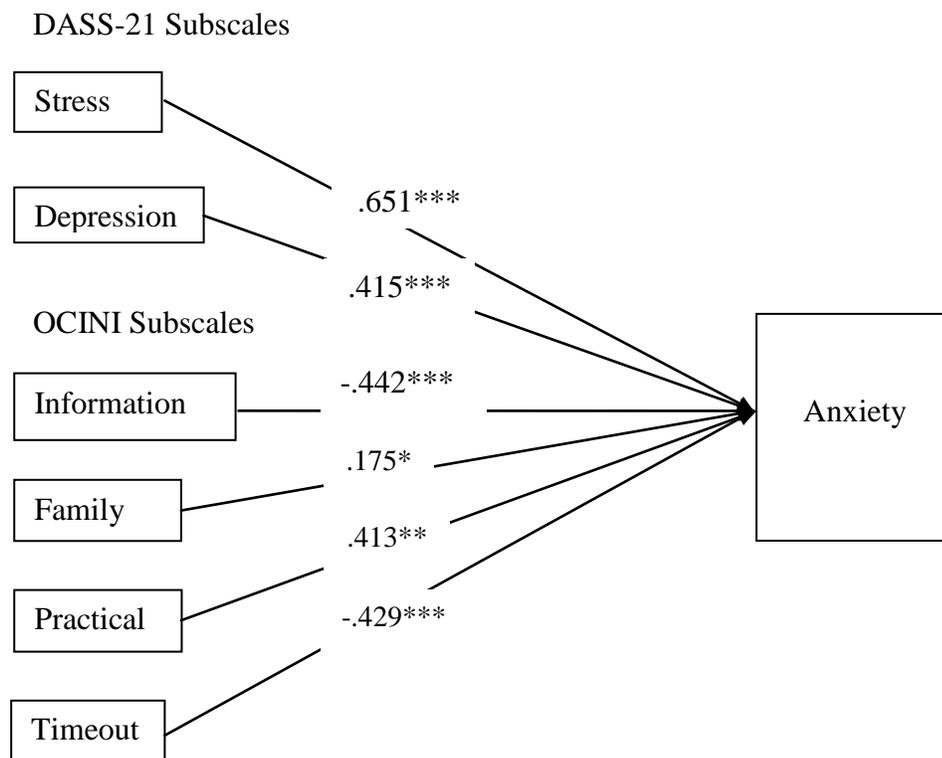
Model one, containing demographic variables, accounted for 14.2% of the variance in anxiety $R=.419$ ($F(4,100) = 5.319$, $p < .001$). Model two contained outcome variables of quality of life, stress, and depression. The model had a significant r^2 change = .573, and accounted for 74.8% of the total variance. $R=.865$ ($F(7,97) = 41.221$, $p < .001$). Block three contained the final model of the seven OCINI subscales. The OCINI variables contributed a significant r^2 change of .073, and the entire model accounted for 79.4% of the total variance, $r = .906$ ($F(14,90) = 29.630$, $p < .001$).

Table 4.5 shows the relationship direction, standardised Beta weights, part, partial and zero-order correlation. The analysis of this data indicates that significant variables have stronger zero-order correlation with anxiety than the part and partial correlation. This indicates that there is shared power in the variance of anxiety when the other variables are present.

The model suggests that stress and depression are good predictors of anxiety. The more the young adult has a need for family support and practical assistance, the more anxious they feel. Yet the more they have a need for information and timeout, the less anxious they are.

Figure 4.2 illustrates the significant predictors and standardised Beta weights of the anxiety model highlighting variables which may make individuals at more risk of anxiety.

Fig 4.2 Anxiety Model



Key = * p<.05; ** p<.01; *** p<.001

Table 4.5 Showing beta, Standardised Beta Weights, Significance, Zero, Part and Partial Correlations for Anxiety

Variables	B	Beta	t	p	Zero order	Semi partial	Part
Stress	.563	.651	6.135	.000	.825	.543	.273
OCINI Information	-.384	-.442	-3.806	.000	.636	-.372	-.169
OCINI Timeout	-.664	-.429	-3.882	.000	.597	-.379	-.173
Depression	.330	.415	4.062	.000	.821	.394	.181
OCINI Practical	.379	.413	3.043	.003	.695	.305	.135
OCINI Family	.347	.175	2.155	.034	.613	.221	.096
OCINI Feeling	.096	.165	1.315	.192	.664	.137	.059
Time ill OCINI Sup young adults	-.058	-.120	-1.968	.052	-.346	-.203	-.088
OCINI Friends	-.179	-.086	-1.331	.187	.348	-.139	-.059
	-.106	-.057	-.750	.455	.484	-.079	-.033
Sex of participant	-.314	-.041	-.784	.435	-.230	-.082	-.035
QoL	.007	.020	.179	.858	-.679	.019	.008
Age of participant	-.035	-.012	-.241	.810	.053	-.025	-.011
Type of parental illness	-.014	-.007	-.148	.883	.080	-.016	-.007

4.3.3.3 Stress

The Durbin Watson Statistic for auto correlation was 1.650, which is within the permitted parameters for independence of residuals. Normality and homogeneity of variance were not violated.

Model one, containing the demographic variables, accounted for 16.4% of the variance in stress $R=.443$ ($F(4,100) = 6.086$, $p < .001$). Model two contained outcome variables of anxiety, quality of life, and depression. The model had an r^2 change = .590, and accounted for 78.6% of the total variance. $R=.887$ ($F(7,97) = 50.886$, $p < .001$). Block three contained the final model of the OCINI subscales. The OCINI variables contributed a significant r^2 change of .090, and the entire model accounted for 87.6% of the total variance, $r = .936$ ($F(14,90) = 45.318$, $p < .001$).

Table 4.5 shows the relationship direction, beta, standardised Beta weights, part, partial and zero-order correlation. The analysis of this data indicates that significant variables have stronger zero-order correlation with stress than the part and partial correlation. This indicates that there is shared power in the variance of anxiety when the other variables are present.

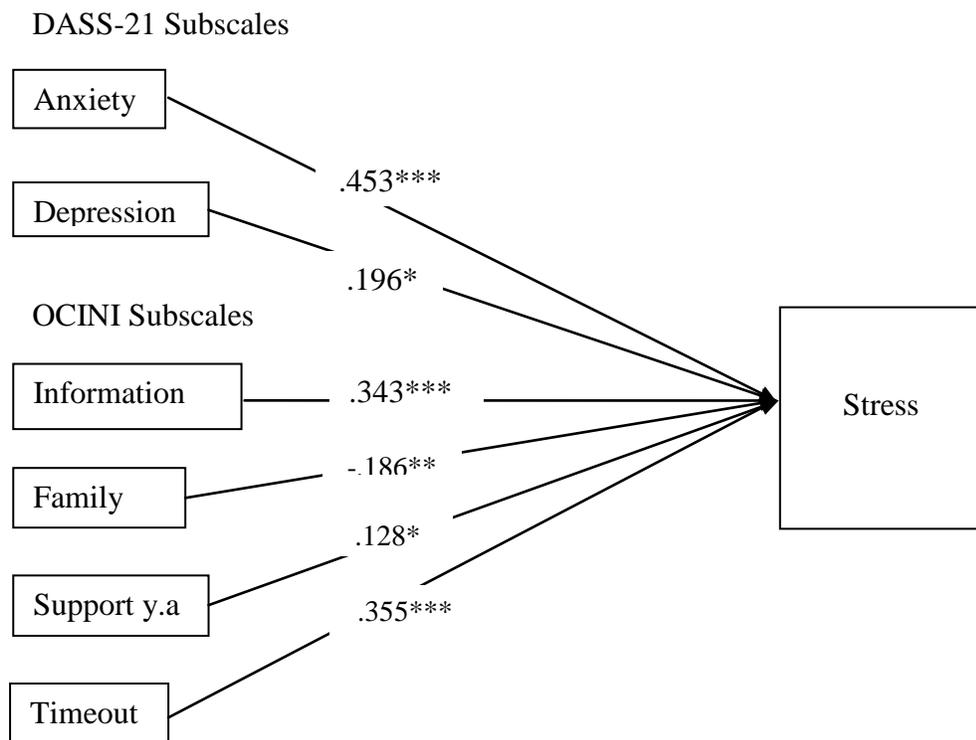
As predictors the *need for information*, *timeout*, and *support* increases, so does the criterion of stress. *Need for family support* has a strong negative correlation with stress, indicating that the more the adolescent needed their family's support, the less stressed they were.

Table 4.6 Showing beta, Standardised Beta Weights, Significance, Zero, Part and Partial Correlations for Stress

Variables	B	Beta	t	p	Zero order	Semi partial	Part
Anxiety	.524	.453	6.135	.000	.825	.543	.228
OCINI Timeout	.634	.355	3.845	.000	.763	.376	.143
OCINI Information	.345	.343	3.501	.001	.770	.346	.130
Depression	.180	.196	2.169	.033	.833	.223	.081
OCINI Family	-.427	-.186	-2.789	.006	.571	-.282	-.104
OCINI Feelings	-.113	-.169	-1.625	.108	.689	-.169	-.060
OCINI Sup young adults	.308	.128	2.426	.017	.489	.248	.090
OCINI Practical	-.110	-.104	-.878	.382	.764	-.092	-.033
QoL	-.043	-.104	-1.098	.275	-.753	-.115	-.041
Time ill	.036	.064	1.243	.217	-.376	.130	.046
Type of parental illness	.115	.052	1.260	.211	.091	-.132	-.047
OCINI Support friends	-.110	-.051	-.810	.420	.486	-.085	-.030
Adolescent age	-.174	-.050	-1.268	.208	.020	-.132	-.047
Adolescent gender	-.376	-.042	-.975	.332	-.225	-.102	-.036

Figure 4.3 illustrates the significant predictors and standardised Beta weights of the stress model highlighting variables which may make individuals at more risk of stress. This model could be of benefit to counselling psychology practice as it indicates the variables which influence an individual's stress levels.

Fig 4.3 Stress model



Key = * p<.05; ** p<.01; *** p<.001

4.3.3.4 *Quality of life regression*

The Durbin Watson Statistic for auto correlation was 1.611, being within the permitted parameters for independence of residuals. Normality and homogeneity of variance were not violated.

Model one, containing demographics, accounted for 38.5% of the variance in quality of life $R=.639$ ($F(4,100) = 17.254$, $p < .001$). Model two contained outcome variables of stress, anxiety and depression. The model had a r^2 change = .334, and accounted for 74.2% of the total variance. $R=.862$ ($F(7,97) = 39.909$, $p < .001$). Block three contained the final model of the seven OCINI variables, which contributed a significant r^2 change of .106, and the entire model accounted for 82.5% of the total variance, $r = .921$ ($F(14,90) = 35.974$, $p < .001$).

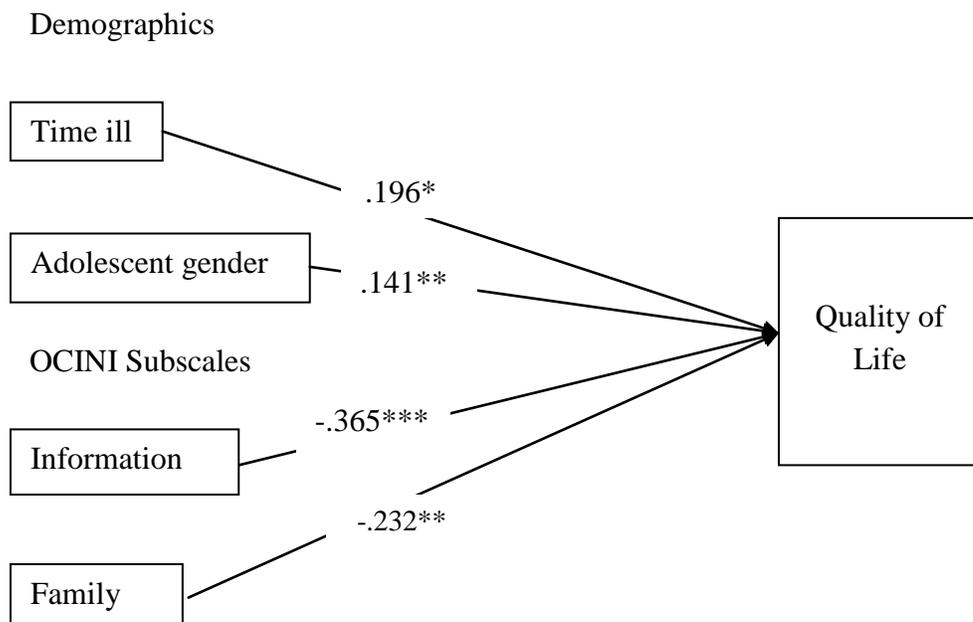
Table 4.7 shows the relationship direction, beta, Standardised Beta weights, part, partial and zero-order correlation. The analysis of this data indicates that significant variables have stronger zero-order correlation with quality of life scores than the part and partial correlation. This indicates that there is shared power in the variance of anxiety when the other variables are present. *Need for information* and *the need for family support* have a strong negative zero-order and part and partial correlation with quality of life. The more adolescent children needed information and family support, the lower they recorded their quality of life.

Table 4.7 Showing beta, Standardised Beta Weights, Significance, Zero, Part and Partial Correlations for Quality of Life

Variables	B	Beta	t	p	Zero order	Semi partial	Part
OCINI Information	-.896	-.365	-3.355	.001	-.863	-.333	-.138
OCINI Family	-1.300	-.232	-3.185	.002	-.768	-.318	-.131
Time ill	.239	.175	3.230	.002	.537	.322	.133
Depression	-.359	-.160	-1.581	.117	-.748	-.164	-.065
Sex of participant	3.047	.141	3.059	.003	.319	.307	.126
Stress	-.311	-.127	-1.098	.275	-.753	-.115	-.045
OCINI Timeout	-.518	-.118	-1.084	.281	-.677	-.114	-.044
OCINI Feelings	.175	.107	.920	.360	-.667	.096	.038
OCINI Sup Friends	-.551	-.105	-1.510	.135	-.569	-.157	-.062
OCINI Sup Young Adults	.365	.062	1.038	.302	-.356	.109	.043
OCINI Practical	.153	.059	.451	.653	-.764	.047	.018
Age of Y A	-.362	-.043	-.973	.333	-.161	-.102	-.040
Type of parental illness	-.208	-.039	-.841	.403	-.116	-.088	-.035
Anxiety	.049	.017	.179	.858	-.679	.019	.007

Figure 4.4 illustrates the significant predictors and standardised Beta weights of the quality of life model highlighting variables which may make individuals rate their quality of life scores poorly. This model could be of benefit to counselling psychology practice as it indicates the variables which influence an individual's stress levels.

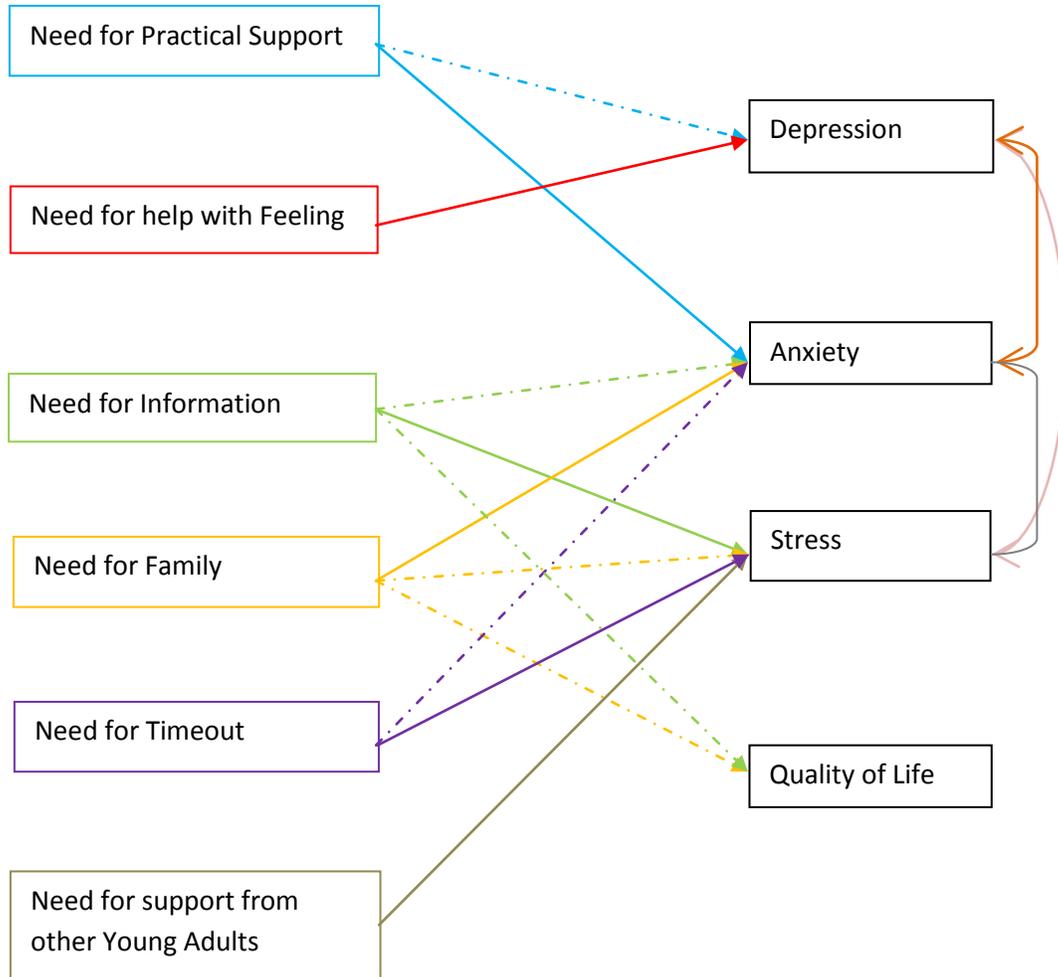
Fig 4.4 Quality of Life Model



Key = * $p < .05$; ** $p < .01$; *** $p < .001$

The analysis has illustrated significant strong negative associations between OCINI and quality of life variables, and strong positive associations between the all of the OCINI variables and between the OCINI and DASS-21 variables. Some OCINI variables predicted criterion variables. These results can be triangulated with the evidence found earlier in the thesis.

Fig 4.5 Showing OCINI Predictor Variables for Depression, Anxiety, Stress and Quality of Life



Key ———> positive association

- - - - -> negative association

4.4 DISCUSSION

This study quantitatively investigated type and frequency of unmet psychosocial and supportive care needs, and their association and predictive power with self reported affect, coping and quality of life outcome scores. The findings will be discussed in conjunction with the theoretical framework of ecological systems theory (Bronfenbrenner, 1979), symbolic interactionism (Blumer, 1969) and conservation of resource theory (COR; Hobfoll, 1989; 1998). Type of adolescent unmet need, its association with affective state and the variability of unmet needs between NCD and cancer will be discussed; these will be examined through comparisons between the OCINI and OCNI (Patterson, *et al*, 2010).

4.4.1 Hypothesis One

4.4.1.1 Access to external practical support

Hypothesis one stated that young adults will have a variety of psychosocial and supportive care needs. This hypothesis can be accepted. Demographic data explored how many participants had been in receipt of information or support. Participant numbers were not equal between groups, yet analysis of demographic details revealed some interesting findings.

The *stroke* and *epilepsy* subgroups received more information than other groups. These conditions have a high speed of onset and accelerated severity if medical interventions are not quickly administered. Information would likely ensure the family knows what constitutes as an emergency and how to react. This may inadvertently place more responsibility and pressure upon the adolescent to recognise an emergency and act appropriately.

Gender of the ill parent may have contributed to the adolescent's access to external practical support; the epilepsy category, which contained a higher proportion of mothers, had a higher frequency of practical assistance. This could be due to the traditional caregiver being the patient (Stone, et al., 1987), thus increasing societal perception of need for help (Blumer, 1969). Within psycho-oncology literature, Kennedy and Lloyd-Williams (2009b) suggest that practical information was needed after information about the condition had been received and parental illness continued, however they did not specify an optimal time for the transition of factual information to practical information (Kennedy & Lloyd-Williams, 2009b).

4.4.1.2 *Frequency and variety of unmet needs*

The variety and frequency of unmet needs were tested through rank ordering unmet psychosocial and supportive care need items on the OCINI questionnaire. The three most frequent needs on the OCINI follow, the fulfilment of gaining access to a resource could fill a variety of needs: (1) *the need for support from friends*, would help the young adult feel connected within their peer group, thus regaining the adolescent identity of them-self (Erikson, 1968) and be a source of emotional and compassionate support (Schwarzer & Leppin, 1991); (2) *the need to feel that parents were being open*, and *the need to feel informed about the condition* (joint second), have an overall theme of being informed. Parents being receptive could assist the adolescent in feeling included and acknowledged within the illness experience; affecting informational needs due to increased access to illness status, thus fostering a more conducive family environment for emotional expression and information exchanges about the illness (Afifi & Olson, 2005). (3) *The need to be able to express how I feel about my parent's illness without worrying about upsetting people* would have had many aspects of it fulfilled through open communication with friends and

family which would likely help them off-load. Openness of conversation and experience may reduce the adolescent's drive to protect others.

The OCNIIs (Patterson, *et al*, 2010) most frequent current unmet psychosocial and supportive care needs were: (1) the *need for understanding from friends*; (2) the *need for support from friends*; and (3) the *need to have fun*. These needs all consist of spending quality teenage time with friends away from the illness environment. It was noted that *need for parents to be open* was not a prominent requirement in the OCNI analysis; this could be due to recruitment being made through a cancer centre where parents are service users, thus suggesting a certain level of openness due to parents informing their child of the study.

The three lowest ranking questions for the entire OCINI scale were: (44) the *need to be linked with social support networks*; (45) the *need for aiding independence*; and (46) the need for help managing *changes in the parental relationships*. The organisations involved with participant recruitment were geared toward helping 'young carers' and may have ameliorated the need for support and information from others with shared experiences. Northouse and Swain (1987) suggest that meeting individuals in similar situations is beneficial in knowledge and experience sharing. Parental relationships may not have overtly changed greatly as analysis from Chapter Three showed that the individual worked hard to protect their parent from additional emotional concern by acting 'normally'.

Patterson *et al* (2010) found that 97.4% of the adolescents who have a parent with cancer had at least one need. This study had slightly less at 93.5%. Unmet psychosocial and supportive care needs of adolescent children who have a parent with a NCD vary between the interpersonal and

intrapersonal and appear to be comparable to the needs of young adults who have a parent with cancer.

4.4.2 Hypothesis Two

Hypothesis two suggested young adult's quality of life and affective state would be associated with their unmet psychosocial and supportive care needs. This hypothesis can be accepted.

Depression, anxiety and stress scores were all low to moderate, as measured by the DASS-21 (Henry & Crawford, 2005) standard scores. Edwards and Clarke (2004) suggest that family members can have varying levels of anxiety, stress and depression. Some of the psychological and emotional hardships felt by family members could be the product of hopelessness or adjustment, which has different characteristics to depression (Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR), 2000).

Effect sizes between OCINI variables were large indicating shared co-variance; unmet need variables overlapped and were co-dependent rather than independent. Needs overlapping is a reasonable finding as the scale measures need; the evidence throughout the thesis suggests that meeting one need influences other needs. Meeting specific needs, such as *need for support from friends*, appears to have a ripple effect in fulfilling other needs, which in this case could increase the adolescent's access to information, and emotional and social support. Needs-based interventions would likely benefit many areas of the young adult's life.

Strong positive effect sizes were noted between needs, negative affective state, anxiety and stress (Hobfoll, 1989; 1998). The OCNI (Patterson, *et al*, 2010) used an overall score of unmet needs to analyse depression, anxiety and stress variables, with results producing strong positive

associations. This chapter broke the overall unmet needs score down into each OCINI subscale (i.e. information, family, peer support) in order to gain more information. The effect sizes of all OCINI subscales were considered to be moderate to high (Cohen, 1988). These were comparable to Patterson *et als* (2010) findings with the parental cancer population, indicating that unmet needs and affective state have a similar association in individuals who have a parent with a NCD or cancer.

4.4.3 Hypothesis Three

It was hypothesised that unmet psychosocial and supportive care needs will predict self reported affective state and quality of life. Regression analysis was used to test this hypothesis, findings show that certain unmet needs are good predictors of self reported anxiety, stress, depression and quality of life.

4.4.3.1 Stress

Stress occurs when resources are threatened, lost, or invested without subsequent gain (Hobfoll, 1989; 1998; Hobfoll & Lily, 1993). Interpersonal relations, such as social support and individual differences can moderate the stress response (Schwarzer & Leppin, 1991). This suggests that unmet needs due to a threat or loss of resource are positively associated with increased stress, which interpersonal relationships can help to ameliorate. The stress model found that the *need for support from other young adults* who also had an ill parent had a low, yet significant positive association with increased stress (Northouse & Swain, 1987). Shared experience could make adolescents feel part of a group where they were understood by others who had experienced the conscious and unconscious intricacies involved with parental illness. This would give them

opportunity to reframe concepts (Blumer, 1969), and identify with other adolescents (Erikson, 1968).

Need for support from friends was a prominent need based upon the individual OCINI items, though the need the friends subscale was not a significant predictor within the models.

Attachment style mediates an individual's ability to regulate emotions (Schoore, 2000). The adolescent transitional stage of development can bear influence upon an individual's identity and ability to use supportive networks (Joubert, et al., 2001; Taylor, Gibson & Franck, 2008). The illness experience may change relationships with friends, making peer introjections and support less meaningful and attainable (Blumer, 1969; Taylor, Franck, Dhawan, & Gibson, 2010).

The *need for information* and the *need for timeout* from the illness experience were found to be significant positive predictor variables of increased stress, which is consistent with the needs of adult formal and informal caregivers (Given *et al*, 1992). Barriers to accessing information are more prominent in adolescents (Foucault, 1988) and it is likely that this influenced accessibility to information.

A significant negative association between the *need for family support* and stress was noted. The need to protect family members from the psychological and emotional hardships due to the illness experience was noted in Chapter Three. Protecting parents was an important role for the young adults. These findings may suggest that keeping their parents safe, and not being the focus of family 'interventions' reduced young adults stress levels, or increased their awareness of stress. However, causation cannot be determined; therefore the analysis may be indicative of the most stressed individuals already receiving support from their family.

4.3.3.2 *Anxiety*

The anxiety model found interesting negative associations between the *need for information*, the *need for timeout*, and anxiety.

The analysis in Chapter Three found evidence indicating that young adults wanted to remain with their family whilst their parent was ill to assess their condition due to them feeling uninformed by family members. By going out the adolescent may feel that they had less information about their parent's condition, thus making the situation seem more threatening, thus increasing anxiety levels.

The findings of this study differ from Watson, St James-Roberts, Ashley, *et al.*, (2006) who found information reduced anxiety in children with parents who have cancer (when compared with children who did not receive information). This may be due to the information being inadequate in timing or content or due the most anxious individuals within this study already receiving all of the information they required. The need had reduced yet the emotion remained present.

4.4.3. Depression

The depression model found a small positive association with length of parental illness, with daughters being more depressed than sons. Literature on adjustment in ill individuals has found that negative affective state is associated with increased time and pain (Chaney, *et al*, 1996). The findings suggest that as length parental illness increases, the young adult becomes aware that the situation is enduring and that their life has been altered as a result (Burton, *et al*, 2003; Hirst, 2005). This was suggested in Chapter Three, yet other participants from the same study stated that time makes things more manageable. Attachment style, personality type or another

mediating variable which has not been accounted for within this study may influence affective state, coping, and unmet psychosocial and supportive care needs.

Bauman, et al., (2001) suggested that daughters were more depressed than sons due to their taking on an emotionally supportive role. Douvan and Adelson (1966) suggest females identify themselves through social roles and perceptions; as such a care-giving identity could be more readily assimilated with daughters. If peers do not recognise the adolescent's new identity it could affect their friendship and impact upon the availability of support mechanisms (Zarit, *et al.*, 1980), limiting access to available support systems.

A moderate negative association was noted between the need for practical assistance and depression. It may be that an individual who is able to be practical has cognitive defences which protect against depression, that proactively assisting their parent, they felt less depressed and more in control, or that the most depressed individuals had already had access from external practical support.

4.4.3 *Quality of life*

The need for family support and the need for information were negatively associated with self reported quality of life scores. The model suggests that by ensuring the family unit remains communicative and that adequate information is available, the adolescent child's quality of life would increase.

Quality of life was not a significant predictor of depression, anxiety or stress outcome variables; literature suggests that affective state and quality of life share a multi-directional relationship (Hulbert-Williams, Neal, Morrison, Hood & Wilkinson, 2012). Quality of life has been tested in

a variety of children and adolescents, with results finding it to be a stable construct and measurable (Langeveld, Hoot, Loonen, Hazebroek-Kampschreur, & Passchier, 1996). The present study found no such association between quality of life and affective state. The quality of life scale has been specifically designed for informal carers, aged 19-93 years. It contained words which were synonymous with caring and carer, these may not have resonated with the lived experience of the young adult as they did not feel that they could be classified as a carer; this lack of identification and belonging with the label of 'carer' was noted in Chapter Three. Items associated with the negative consequences of caring may have caused some feelings of guilt, as analysis from Chapter Three suggested that young adults value being able to look after their parent and feel empowered to live a more independent life.

4.5 STUDY CRITIQUE AND EVALUATION

This chapter will be critiqued using the CASP (2006) for quantitative research. This study quantitatively investigated unmet psychosocial and supportive care needs of adolescent children who have a NCD by using three scales, two of which were new. In order to determine the reliability of the scales used within this chapter, reliability analysis using Cronbach's alpha was calculated; results suggest the scales have good internal consistency.

The sample design used in this study provided a time efficient and effective way of collecting data in the initial investigation of a new area of research, however due to the population being from a cross sectional cohort, cause and effect is not readily available; the data cannot determine if one variable was the cause or the effect of another variable. The stability and duration of emotions and need variables may have acted as confounding variables. Emotions (e.g. depression, stress and anxiety) and appraisals (e.g. quality of life) could be considered to be more

permanent and resistant to immediate change, whereas 'needs' change in a very short space of time as they are reactionary to the loss of a resource, or the act of trying to regain homeostasis (Hobfoll, 1989; 1998). This could also impact upon interpretation of the results as the cross-sectional sample is unable to determine cause and effect.

Participant numbers fell below the recommended participant to variable ratio (Green, 1991). However, subsequent analysis using G*Power indicated that the model was sufficiently powered. The effect sizes noted within the analysis are comparable to unmet needs with adolescents who have a parent with cancer. Data were screened to determine type of distribution (i.e. parametric or heterogeneous). Analysis was conducted using parametric tests on a sample which had been screened to exclude multivariate outliers, which could skew the results.

The results of this study can be related to qualitative research contained within this thesis and to published research conducted in psycho-oncology which investigates the unmet psychosocial and supportive care needs of young adults who have a parent with a cancer diagnosis. Furthermore, the results from this chapter give good evidence to continue conducting research into the unmet psychosocial and supportive care needs of individuals who have a parent with a NCD as it would be beneficial to the current and future psychological well-being (Watson, *et al*, 2012).

4.6 IMPLICATIONS FOR COUNSELLING PSYCHOLOGY PRACTICE

Counselling Psychologists work with individuals who experience low mood, anxiety, and stress and are trying to adjust to changes in their life. Change is something which can create fluctuations in survival strategies with social support being a useful coping mechanism (Schwarzer & Leppin, 1991). For adolescents, this can be further impacted due to attachment

processes making social relationships and parental detachment important in the development of the adolescent's identity (Bowlby, 1969).

This study has highlighted many issues which could inform counselling psychology practice.

This analysis begins to explore the predictive powers of unmet psychosocial and supportive care needs upon affective state of young adults who have a parent with a NCD. The findings produced models depicting the effect size and direction of association between unmet needs, anxiety, depression, stress and quality of life. It also highlights demographic variables which also had predicted the outcome variables.

These models can be applied to therapeutic practice as they provide the therapist with information about precipitating factors to negative affect and well-being, thus giving a meaningful starting point for therapeutic dialogue. From this study we know that a child presenting with depression is likely to have a need for help with feelings, less likely to have a need for practical assistance, and would likely have increased anxiety and stress. The knowledge gained from the model could signpost the therapist to areas where their client may be experiencing difficulties, and could be a good starting point to talk around. The models would contribute to therapeutic formulations, which are a useful aid in illustrating maintenance cycles, reciprocal roles, in providing psycho-education and a meaningful beginning to therapeutic dialogue (Ryle, 1990).

Being able to communicate with individuals who have shared experiences is an important need.

Group work would be a beneficial form of therapeutic intervention as it would give clients chance to talk about their experiences and hear other people's narratives. The shared therapeutic experience would not only meet emotional and potentially some timeout needs, but would likely

go some way in meeting informational and practical needs due to an increase in social introjections, moderating negative affective state (Schwarzer & Leppin, 1991).

4.7 CONCLUSION

The analysis provided within this study gives good evidence to suggest that unmet psychosocial and supportive care needs are significantly associated with self-reported affective state, stress, anxiety, and quality of life scores. There is need for more research preferably using longitudinal designs to determine causal relationships between unmet psychosocial and supportive care needs and affect. The models produced within this study offer a useful tool for therapists to consider within their therapy sessions. It may be beneficial to determine the effect that attachment style and personality type has upon need and emotional response. It could be suggested that the type of need required could be moderated by the attachment system. Hunter and Maunder (2001) found that anxious ill individuals wanted to receive information and advice directly from medics, where as avoidant individuals preferred to receive information through their own endeavours. However attachment and personality styles may pose some difficulties in measurement during adolescence due to their stability being a controversial subject with regards to adolescence.

CHAPTER FIVE
THESIS CONCLUSION

5.1 BACKGROUND

This thesis aimed to investigate the unmet psychosocial and supportive care needs of young adults who have a parent with a NCD. It was conceptualised that the theoretical frameworks of symbolic interactionism (Blumer, 1969), ecological systems theory (Bronfenbrenner, 1979) and conservation of resources theory (Hobfoll, 1989; 1998), would together offer insight into how illness experiences and access to resources could be conceptualised by adolescent children. The aims of this thesis were to pragmatically investigate the unmet psychosocial and supportive care needs of young adults who have a parent with a NCD; the discussion was related to the theoretical framework.

5.1.1 Current Literature

A narrative literature review was conducted to conceptualise the current knowledge on unmet psychosocial and supportive care needs of ill individuals, and formal and informal caregivers during the illness experience. The majority of findings related to psycho-oncology, with informational needs being universally requested. It was noted that ill individual's needs were more identifiable by carers than patients, thus being a barrier to accessing external support if clinicians did not ask carers about needs. Unmet needs of formal and informal carers were associated with caregiver burden and the carers' ability to help the ill individual (Schubert, *et al*, 2008).

A more focused systematic review of published literature was conducted to capture research which investigated the first-hand accounts of unmet needs of young adults who

have an ill parent. Owing to there being a noticeable increase in studies related to psycho-oncology in the narrative review, the systematic review was broadened from NCDs to include cancer and psychological problems. Findings indicated that adolescents needed information, recreation, and social support, and that unmet needs were associated with negative affective state. It was noted that adolescent's didn't want to worry their parents or upset them by asking questions. When this was coupled with the findings from the narrative review, which suggested that parental reports downplayed the impact of illness upon their children, it highlighted the importance of gaining first-hand accounts of unmet needs; the search results showed that such literature was sparse.

5.1.2 IPA Study

To bridge the gap in the literature exploring the adolescent's conceptualisations and experiences of unmet needs when they have a parent with a NCD, an IPA study was conducted. The analysis revealed four highly interdependent emergent themes, two being interpersonal (*support needs* and *information needs*) and two intrapersonal (*need for acknowledgment* and *need to be them-self*). Analysis suggested that various unmet needs were multidirectional (see fig 3.1). Due to the interdependent themes, analyses suggested that the fulfilment of one need had the ability to impact upon and partially meet other needs. E.g. by being given *information*, the adolescent was also being *acknowledged* and included; therefore their role as a member of the family caring 'team' was less *secret*. The analysis indicated that unmet needs and affective state were associated, and that the themes were comparable to subscales on a newly designed

measure (OCNI; Patterson, *et al*, 2010) of unmet needs with children who had a parent with cancer. The OCNI measured how much an individual had an unmet need within seven specific subscales of *information; family; friendship; timeout; support from other young adults; feelings; and practical assistance*. It was suggested that quantitative research would be well placed to test the association of unmet needs with affective state and to assess whether needs varied between NCDs and cancer, through using a quantitative measure.

5.1.3 Quantitative Study

The quantitative analysis in Chapter Four used data from a revised version of the OCNI (Patterson, *et al*, 2010), namely the OCINI, to investigate the prevalence and consequences of unmet need on affective state and quality of life of young adults who have a parent with a NCD. The findings indicated that OCINI variables were co-dependent and correlated with anxiety, depression, stress and quality of life variables. Further analysis informed models which indicated that OCINI predictor variables were statistically associated with outcome variables of anxiety, stress, depression, and quality of life. The direction of relationship between these variables, in the main, suggested that the more an individual required a resource, the more they felt a negative emotional effect or reduction in their quality of life. There were however some variables which had the opposite effect, for example, the more an individual had an unmet need, such as practical support, the better their depression score. Due to the sampling method being a cross sectional cohort, cause and effect could not be determined as data was not longitudinal. The quickly changing pace of needs and more enduring effects of

emotional regulation limited statistical interpretation. Needs can change on a minute to minute basis based upon environmental, intrapersonal and interpersonal feedback.

Emotional state can be influenced by internal and external factors, yet these can take time to change. For example an individual with reactive depression, to losing their job, may, by finding another job have some of their worries soothed, yet the remaining core concepts from such an event (i.e. vulnerability, self worth, etc) may take longer to abate.

5.2 SYNERGISED FINDINGS

Published research thus far has investigated the challenges that formal and informal adult carers can face when caring for individuals who are acutely ill or palliative. It could be postulated that adults have more power (Foucault, 1988) to obtain the resources they need and a more mature supportive network, which has been shown to help alleviate negative affect and stress. Even so, research suggests that adult caregivers can still experience interpersonal communication issues (Morris, *et al*, 1988; Savundranayagam, *et al*, 2011), embarrassment, resentment and isolation from society (Kelly, 2010; Zarit, *et al*, 1980).

The research contained within this thesis focused upon young adults and their experiences of caring for their parent with a NCD, which is more long-standing, cyclical, and unpredictable than individuals who have either an acute or terminal disease. The teenage population would likely have a less mature peer support group and less developed abstract reasoning skills (owing to adolescence being a transitional time from child to adult in emotional, physical, and cognitive development), this would bear influence upon their coping and needs.

The sporadic nature of NCD's would make planning difficult and as such it's likely that the watchful waiting would keep an individual on high alert, thus making relaxation and recreation difficult, and reinforcing the idea that the world is not safe or predictable and that their parents are vulnerable. The existential issues which accompany illnesses can be a challenging and abstract concept to face. Individuals tend to think their family members are immune from harm and when this premise is compromised, understandably it can impact upon them emotionally. It is likely this would impact adolescents more readily due to their still being dependent upon their parent; the unpredictability and long-standing nature of the illnesses once again emphasising that their family are vulnerable and unprotected. These concepts are challenging for formal and informal adult caregivers, for adolescents who are just beginning embark on more abstract thinking and reasoning it would likely be a turbulent time; the vulnerability of their family situation and their desire to protect them from more harm or upset would increase their felt pressures and impact upon their well-being.

The cumulative findings of the thesis show that adolescent children have a plethora of unmet needs, (i.e. *information, acknowledgments, peer support, practical assistance*), which are associated with well-being; the unmet needs are comparable to those of formal and informal adult carers (Moser, *et al.*, 1992) and young adults who have a parent with cancer (Patterson, *et al.*, 2010). Needs were interdependent, this was inferred to within the analysis of Chapter Three, and statistically evidenced within the high correlation values between the OCINI variables. Owing to the interdependence of these variables it was suggested that meeting one need would likely meet other needs. The

quantitative findings in Chapter Four suggest that the various needs have predictive power over the criterion variables (see Fig 4.5).

It is noted that the *need for practical support* is a positive predictor of anxiety and a negative predictor of depression. The items relating to depression on the DASS-21 could be conceptualised as being cognitive appraisals of an individual's self worth, meaning and motivation. Analysis from Chapter Three highlighted the adolescent taking on a caring role by doing practical things to help support their parents, these duties may make the adolescent feel as though they are helping and that their behaviour is worthwhile, thus positively impacting upon their self worth and consequently their affective state.

The value the individual puts onto their practical role, was highlighted through the emergent themes in Chapter Three of *The Secret Carer* and *Internalised Pressure*, due to their lack of experience in performing practical duties, or through parentification, their anxiety levels could increase. The systematic review noted adolescent's needed practical information as their parent's condition continued (Kennedy & Lloyd-Williams, 2009_a). By feeling ill equipped, anxiety levels would likely increase for fear of doing something incorrectly or causing harm "*if something went wrong would it be because I had done something wrong*" [T2, Julie, 346-349].

The *need for timeout* was a positive predictor of stress and a negative predictor of anxiety. The analysis from Chapter Three indicates that the adolescents do not feel informed and included in the illness experience; owing to this they prefer to remain close to their parent so they can know what is happening. The items on the OCINI relating to timeout seem to be more focused on interpersonal diversions as opposed to

introspective time alone. Chapter Three's analysis indicated that young adults wanted to be able to be 'snuggled' up safely, and that going out and pretending to have fun was not what they wanted when they were worried about their parent; this may have been one mask too many (Goffman, 1959). It may be that individuals who were anxious would prefer time alone where as those who were stressed preferred the company of others (Schwarzer & Leppin, 1991). The amount an individual relies upon other people during times of stress is mediated by the attachment system (Schore, 2001). The adolescent's attachment style could likely influence their ways of coping during adverse periods, i.e. an anxiously attached individual would likely require more social and interpersonal support than someone who was avoidantly attached (Hunter & Maunder, 2001).

The analysis from Chapter Three suggested that their friendships grew more distant and strained as friends did not understand how their life had changed. Social barriers can be increased through social stigma and misunderstanding surrounding the illness (Corrigan, 2005). Adolescent's may not have wanted to draw attention to their home life (as they wanted to forget their situation), not wanted special treatment, or did not feel safe in divulging information to their friends due to issues surrounding trust and understanding. They would likely relate to other adolescents who had similar experiences and as such found them a source of reassurance. This may go some way to explaining why *need for support from friends* was not a predictor of an outcome variable, but *need for support from other young adults* was a predictor of stress.

The *need for information* variable was a positive predictor of stress and a negative predictor of anxiety, and quality of life. Information being a negative predictor of

anxiety is an interesting finding. This may be due to the most anxious trying to pacify themselves with information, so their need was met, yet their anxiety levels remained. Findings from the systematic review indicate that some individuals want to be given good news (Kennedy & Lloyd-Williams, 2009a); it may be that the honest information, which they sought in the hope of relieving some pressure increased and anxiety levels, did not give them the answers or relief they were hoping for – this was a fear of parents when considering giving their child information.

The *need for family support* variable was a positive predictor of anxiety, and a negative predictor of stress, and quality of life. Analysis from Chapters Two and Three indicated that children wanted to protect their parents from upset, yet required their input to help meet some of their needs. Being the focus of attention may have made it more difficult for the adolescent to block the negative effects of the illness and may have made them feel guilty at taking some of the care away from their parent. By acknowledging the issues, it makes it more difficult to defend their impact.

The analysis noted some interesting gender differences, yet due to the differences between gender sample sizes, findings cannot be generalisable. The analysis in Chapter Two's systematic review noted that females had concerns regarding their future health, yet the literature was biased by participant numbers and detailing gender specific cancers. The IPA analysis in Chapter Three noted that females had concerns about their future health, yet they explicitly stated so, whereas males engaged in more projective ways of dealing with their concern, such as engaging in health protective behaviours, or by focusing upon becoming medically trained. Statistical analysis in Chapter Four

indicated that females who had unmet needs and a parent with a NCD were more likely than males to become depressed. This may be due to females being disproportionately more likely to perform a caring role (Stone, *et al.*, 1987) or due to their undertaking the role of confidant (Bauman, *et al.*, 2001).

Whilst the limited sample sizes used in the studies make any gender differences difficult to generalise to the larger population, there are some interesting results which can be further discussed in relation to societal concepts. The different ways in which the genders managed their emotions and future fears seemed to echo previous research which focused upon gender and emotional expression (Brody, 1985; Piko, *et al.*, 2006), social roles (Stone, *et al.*, 1987) and identity (Sroufe, *et al.*, 2005).

Within many different cultures and societies it is generally noted that females are more readily associated with undertaking a caring role (Stone, *et al.*, 1987), as such, it is likely that daughters implicitly fall into the caring role; this is potentially far more likely when a mother is ill than a father due to the mothers caring for their spouses as part of their caring role. Part of the caring identity also includes tending to the emotional well-being of the ill individual and the family, were appropriate. This would likely impact upon the adolescent's affective state and well-being. Bauman, *et al.*, (2006) found that daughter's were more likely to become depressed due to their being their parent's confidant.

It has been theorised that males and females express emotions in different ways (Piko, *et al.*, 2006), with females inhibiting socially unacceptable emotional responses, such as anger, and internalising negative affect. Males have been found to use more projective types of coping and defence mechanisms. As such these gender differences would make

adolescent children react very differently to having a parent with a NCD. It is also likely that the gender of the ill parent would bear influence upon the caring dynamic, as it could be postulated that mothers with a NCD would be more open to emotional discussions than fathers.

The heritability of illnesses was a notable theme, the fear for future health was explicitly stated by the female participants, yet the male participants expressed the fear in a very different way. This may be due to males using sublimation as a form of coping mechanism, or due to their mothers taking the main caring role, thus reducing the amount of power the adolescent child has; it is likely that the caring dynamics could also skew any emotional or practical hardships. Social support and friendship would impact upon an individual's well-being, it could be theorised that males would find it more challenging to discuss emotional difficulties with their friends.

5.3 THEORETICAL FRAMEWORK

Symbolic interactionism (Blumer, 1969) suggests that reality is based upon individual's concepts, influenced by social introjections from the individual's microsystem, mesosystem, and macrosystem. During periods of change, and loss of resources, individuals can feel increased stress (Hobfoll, 1989) and look towards methods of ameliorating the stress through accessing resources at their disposal (i.e. friends, family, informed others). The analysis in Chapter Three highlights the adolescents attempt to make their microsystem understand the complexity, seriousness and impact of the condition by using medicalised terminology. A headache was medicalised into a 'vascular headache' thus reframing the microsystem's understanding of a headache and

legitimising the condition by linguistically modifying it into a more severe physiological issue; this would also help explain the adolescent's change in circumstances and priorities. The theoretical frameworks contained within this thesis appear to interlink through ecological systems theory (Bronfenbrenner, 1979). See fig 5.1 for illustrated diagram.

(1) The need emerges based upon environmental, interpersonal or intrapersonal feedback regarding the loss of resource or changing circumstances.

(2) The lack of resources has a relationship with negative psychological and emotional affect.

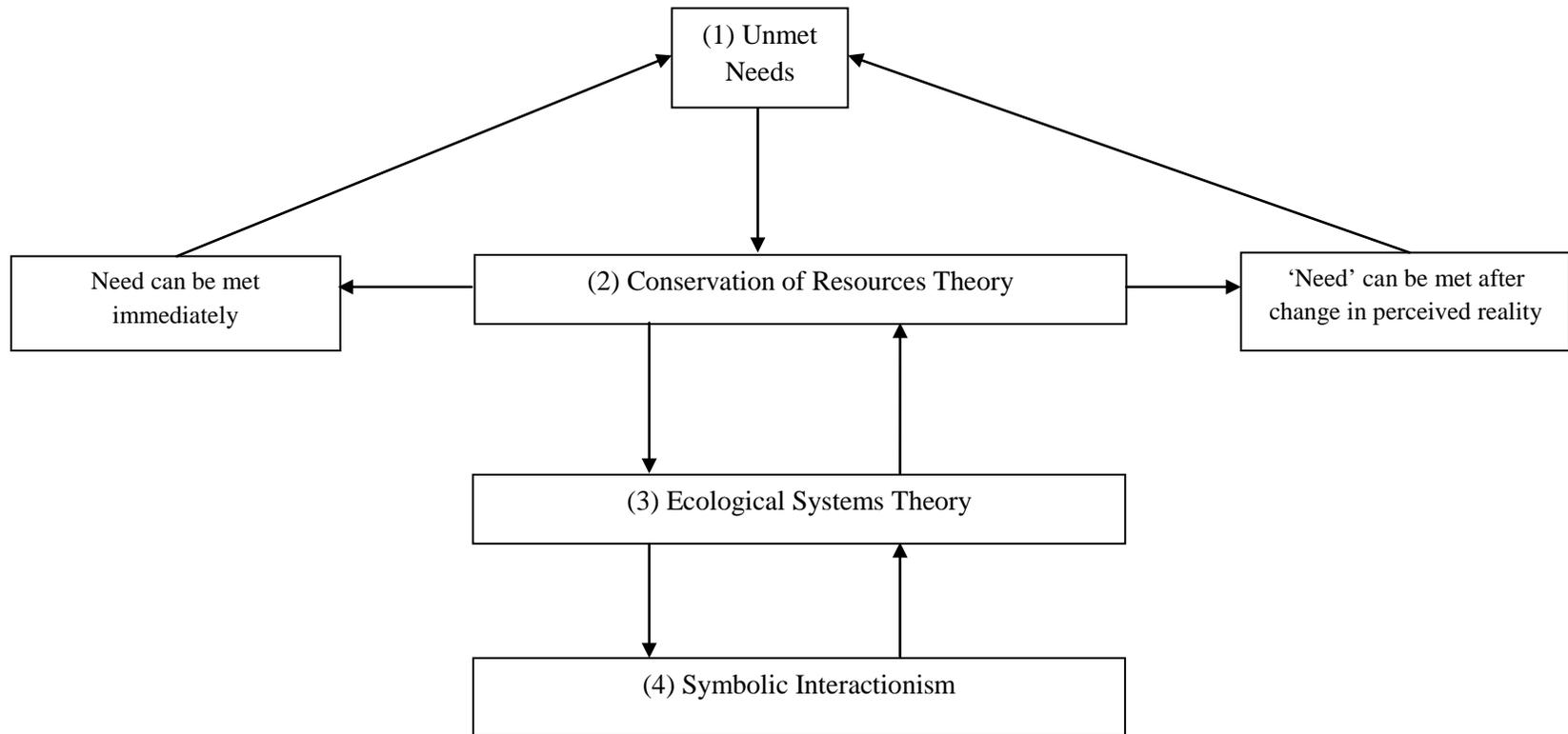
(3) To restore homeostasis, social support systems are sought to meet the need, through their direct input or by them being able to access differing resources.

(4) The social system's ability and willingness to help is based upon the system's understanding of the illness, which is driven by societal perceptions.

In order to demonstrate the above, a case example from IPA study participant *Jayne* [T7], whose mother had been diagnosed with CFS, will illustrate each step, from (1) to (4). Jayne first thought her mother had cancer and reported she needed emotional support and information (1). Due to the changing situation and lack of resources (i.e. information, inclusion, and help with feelings), her narrative conveys that she is in emotional turmoil which she wants to make better (2). Jayne sought the assistance of her peers (3), who were very supportive when she told them that she thought her mum had cancer, due to social understanding of 'cancer' (4). Stage (4) altered when Jayne told her

friends that her mum had CFS. Despite her friends being supportive whilst they believed Jayne's mum had cancer, the diagnosis of CFS changed the seriousness of the condition and they became less supportive and annoyed with Jayne as she couldn't go out with them, even though Jayne's mum was just as poorly as before.

Fig 5.1 Theoretical framework flowchart of direction of unmet needs



5.4 IMPLICATIONS FOR COUNSELLING PSYCHOLOGY PRACTICE

Adolescence is a turbulent time when individuals undergo many different physiological, emotional, psychological and hormonal changes. Changes to cognitions occur and the individual becomes more adept at abstract thinking and reasoning. These formal operations allow adolescents to think about philosophical issues, aspects about their identity, ethical dilemmas, and as such they begin to analyse situations. The ability to consider and analyse in different ways makes the adolescent more aware of their feelings and how these and the feelings of others can influence their well-being (Arnett, 2004; Vygotsky, 1978). Due to the difficult developmental transition time the young adult may require assistance in understanding their changing emotional states.

Counselling psychologists work in many different organisations, and as such have many different routes and skills which could be beneficial to individuals and families who are experiencing changes in their lives. The illness experience would likely bring many issues to the fore, such as existential issues, vulnerability, loss, and feelings surrounding life being unfair – which could link into fate or destiny debates. The findings of this thesis suggest that adolescents who have a parent with a NCD have a variety of unmet needs and that these are associated with their affective state and quality of life.

Counselling psychologists are practitioners who are skilled in providing therapeutic interventions which are underpinned by psychological knowledge and theory.

Counselling psychologist's clinical knowledge and theoretical understanding of issues and processes would be beneficial in helping provide information which was pitched at an appropriate level for adolescents and parents. Practitioner doctorate training focuses

upon becoming an integrative therapist who is able to work with many different issues with individuals, couples, families, and groups.

Counselling psychologists would be well placed within the primary and secondary health care, and educational settings to offer group work for adolescents. Groups would be a forum where the practitioner could offer psycho-education, relaxation techniques and a safe environment where individuals can explore their experiences with other people who have had similar phenomenon, thus being an environment where information exchanges could take place; sharing is an instrumental part of the therapeutic union (Northouse & Swain, 1987). Group work has been found to be beneficial for many different issues, and the stress model in Chapter Four suggests that the *need for support from other young adults* who have had a similar experience is a predictor of stress. The stress model also suggests that information and timeout away from the family would be beneficial for these individuals. This suggests that group work would be beneficial in helping individuals who presented with stress.

Counselling psychologists could offer support to parents through offering them a forum to discuss their fears surrounding their illness, the impact it has had upon their family and offer psycho-education and interventions which could be beneficial to the family unit. By being able to support one another, the illness process would likely be easier to navigate. Psycho-education can help normalise issues and as such, make individuals understand the situation and its impact, thus increasing their sense of self and acknowledgment of the complexity of the illness and subsequent dynamics. The security the adolescent may feel in having a psychological practitioner to call upon in difficult

times may help them feel more able to cope with the changes as they are not free-falling alone.

Medical settings are beginning to bring in more practitioner psychologists who work as part of a multi-disciplinary team which offers a holistic package of care. Hospital services, with the permission of the patient, could provide schools and adolescents information which would be beneficial in explaining about the illness and/or reactions surrounding illness within families. There are many websites currently being used by the NHS for patient and family information, having a reliable database of reputable websites which could be signposted to individuals may also be beneficial, as web-based technology would be accessible when the individual required it and is suggested to be a familiar medium of information retrieval by adolescents (Dina, *et al.*, 2001).

The research in this thesis highlights the complex nature of unmet needs and presents a justified case for further research. Counselling psychologists would be perfectly placed to research the psychosocial and supportive care needs of young adults who have a parent with a NCD owing to their therapeutic and humanistic philosophical ethos of being inductive in stance. Future research will be discussed further in section 5.6.

5.5 THESIS CRITIQUE AND EVALUATION

The studies contained within this thesis have been analysed using methodologies best suited for each respective research question. Each study has been methodologically studied and analysed in different ways, in order to give a holistic overview of adolescent children's unmet psychosocial and supportive care needs when they have a parent with a NCD. There have been critiques about the efficacy and rationale of mixing research

paradigms (Reichardt & Rallis, 1994), yet the results contained within this pragmatic thesis triangulate and inter-relate irrespective of methodology. The findings of the differing studies offer a holistic overview of adolescent children's unmet psychosocial and supportive care needs (Cherryholmes, 1992).

Sample size within the qualitative study was adequate (Smith, 1993); even though there is currently a move to include more participants in IPA research (Reid, *et al*, 2005).

Number of participants in Chapter Four were less than Green (1991) had stipulated necessary for a powered multiple regression, yet G*Power post hoc confirmatory power analysis based on achieved, rather than expected effect sizes, showed that the analyses were sufficiently powered to detect significant effect sizes.

Chapter Four used two newly constructed questionnaires. The Ac-QoL measured quality of life in adult carers (aged 19-93), but a proportion of the participants' ages in this study fell below the lower limit of the age bracket. This may have made invalidated the scale owing to reliability and validity not being test for a younger population thus affecting the standardisation of the scale. Research suggests that quality of life has an interdependent relationship with affective state (Hulbert-Williams, *et al*, 2012). This was not noted within these findings, potentially due to the scale not measuring quality of life within the adolescent child 'carer' population, or due to the participants not recognising themselves as such, as found in Chapter Three's analysis, thus limiting the amount they related to the scale. More research into the quality of life for adolescent children who have a parent with a NCD is needed to help determine how illness may relate to adolescent's children quality of life, this is especially important owing to the multi-

directional relationship quality of life generally shares with affective state (Hulbert-Williams, *et al.*, 2012).

The OCINI was adapted from the newly constructed OCNI: basic psychometric analysis (internal consistency) suggests that revision of the question wording makes the scale relevant to adolescents who have a parent with a NCD. The results from the OCINI study are relatable to the OCNI which investigated needs in the cancer population.

5.6 RECOMMENDATIONS FOR FUTURE RESEARCH

This research offers new insight into an important, yet under researched area. This thesis has identified a new area of research and has gone some considerable way in offering insight into the unmet needs of young adults who have a parent with a NCD.

The findings have the potential to impact upon the entire family unit. Watson, *et al.*, (2012) suggests that appropriate, tailored needs-based interventions are required, but these must be based on a sound empirical base exploring how needs relate to coping and well-being within specific populations

The medium through which needs can be met is an important facet of future research. Determining whether the adolescent child would like their needs met through, for example, information which they could take away and disseminate alone, or through information exchanges with other people, would help ensure that the unmet need was being met in a manner which the adolescent finds meaningful to them. The intrapersonal and interpersonal needs, as conceptualised through the emergent themes in Chapter

Three, may have more obvious routes of being met (i.e. need for social support would be based upon interpersonal communication, whereas need for communication could be met through talking with someone, or through reading information privately). The routes in which adolescents prefer to have needs met may be driven by the adolescent's attachment style (Schore, 2001), anxious-attached individuals may prefer another person to support them through getting their needs met, whereas an avoidant-attached individual may prefer more solitary interventions. Hunter and Maunder (2001) found that anxious patients wanted their clinicians to work very closely with them, whereas avoidant patients preferred to rely upon their own coping resources with little interventions from ward staff. By determining if attachment style did mediate type or resource required, need-based interventions would be better tailored to an individual's coping mechanism, thus making the resource intervention more meaningful, beneficial and suited to the adolescent child.

The fluctuating nature of NCD's and the impact of their unpredictability would be worthy of further research. This would increase knowledge in how to meet needs in adolescents who have a parent with a NCD and help determine if needs vary or fluctuate depending upon the episodic nature of the illness (i.e. do more frequent bouts of illness relapse create more or less need in certain areas?)

Owing to adolescence being an important developmental stage it would be worthwhile investigating if needs differed according to age by determining needs of individuals who were in pre-adolescence. This would highlight any similarities and differences in needs and the 'child's' ability to get them met, as it is reasonable to suppose that needs could

be moderated by society's notion of 'child' vulnerability, which would more likely be associated with younger dependents.

This thesis used a cross sectional cohort, which gave valuable insight and signposted areas of research which require further investigation. It is suggested that a longitudinal sample would be able to offer valuable insight in predictor variables and to begin to determine any direction of causation, thus helping to put appropriate interventions into place before well-being was too detrimentally affected. The investigation of unmet psychosocial and supportive care needs in young adults and children would offer clinicians needs-based interventions which could be applicable for the whole family.

5.7 CONCLUSION

The analysis and findings contained within this thesis provide good rationale for the continued investigation of adolescent children's unmet needs when they have a parent with a NCD. This thesis provides a springboard for many different routes of enquiry to help determine the unmet psychosocial and supportive care needs of young adults, which will provide evidence towards future interventions that will be beneficial in vaccinating individuals against current and future distress (Watson, *et al.*, 2012).

This thesis pragmatically explored the unmet psychosocial and supportive care needs of adolescent children who have a parent with a NCD. The studies contained herewith provide new knowledge and information regarding the unmet needs of young adults who have a parent with a NCD and gives direction of focus to further research; as such, the thesis has fulfilled its aims.

CHAPTER SIX
CRITICAL APPRAISAL
OF THE RESEARCH PROCESS

6.1 INTRODUCTION

6.1.1 Background

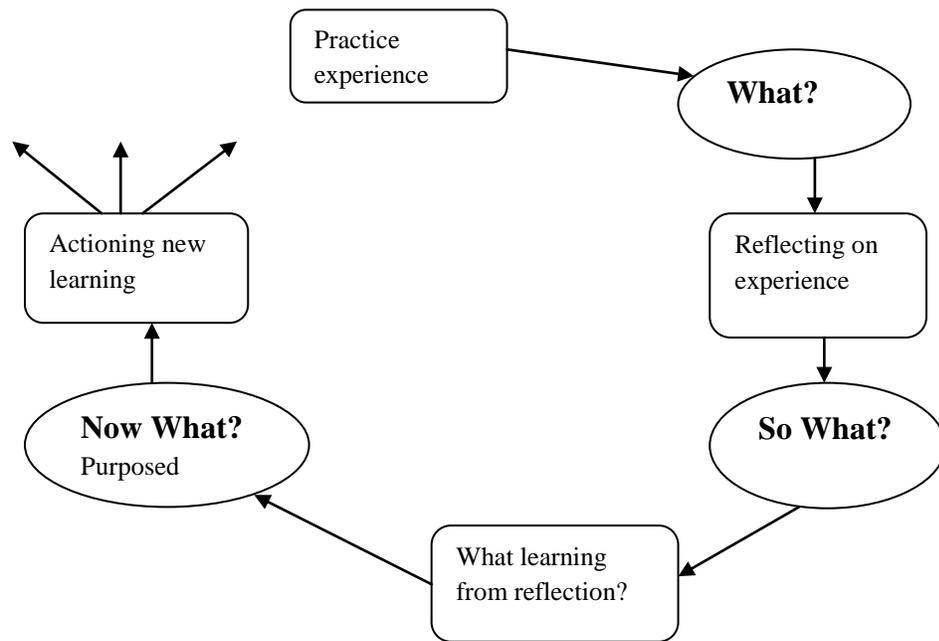
The work contained within this thesis is the result of approximately three years of my endeavours from idea formation through to submission. In this chapter I will use reflective techniques to critique the research process and identify how this research has contributed to my identity as a counselling psychologist and academic. Reflection is conceptualised as the proactive process of evaluating one's own experiences and has roots in experiential learning (Rolf, Freshwater & Jasper, 2001). For this reason it is perfectly suited for appraising my experiential learning whilst conducting my doctoral research dossier.

Borton (1970) provides a framework for guiding reflective activities by incorporating core reflective skills based upon actions by asking: 'What?', 'So What?' and 'What Now?' Driscoll (2000) matched these questions to stages of experiential learning and added questions to form Driscoll's cycle (2000) (see fig 6.1). This critical appraisal of the research process will utilise Driscoll's (2000) framework to make sense of the ways in which this research has been conducted.

Research is an essential part of a psychologist's professional life. Practitioner psychologists use research to help inform evidence based practice, and are well placed

to contribute to knowledge by doing research borne from clinical experience and knowledge. Research is noted as being an important skill for a psychologist to be able to conduct ethically, as stated in 2.3.6 the NHS Knowledge and Skills Framework (KSF, 2010).

Fig 6.1 Showing Driscoll’s Experiential Learning Cycle (2000)



6.1.2 Practice experience leading to the research idea

I first became interested in physical health psychology during undergraduate lectures in psychoneuroimmunology; increased interest led me to become honorary secretary of the British Psychosocial Oncology Society (BPOS) in 2011. This has facilitated my working and networking with other researchers who are investigating unmet needs, and allowed my knowledge base of relevant theory to grow. I have had opportunity to work

therapeutically in different settings with many different clients and settings, including developmental neurosciences and learning disabilities, and physical health and trauma. I currently work in a busy city hospital with individuals who have suffered severe physiological traumas, leading me to develop an interest in the existential issues brought about by ill health and their effects upon family dynamics. It is standard practice to offer psychological support to individuals who have life threatening conditions or traumatic injuries. Ill individuals regularly attend therapy yet entire family units seldom partake even when client issues relate to familial dynamics. The horror of the situation is sometimes only manageable by using psychological defences to block pain; inviting family members to discuss issues would make blocking more difficult as the subject and situation is made more real through its acknowledgement (Firestone, 1983).

During the latter stages of the first year of the doctorate, and at beginning of my research process, I cared for my late mother-in-law when she had pancreatic cancer. This gave me a very different type of understanding of the illness and caring experience. As I began to read further around the illness literature, I realised that I could have added my own experience as a case study. This was a cautionary insight to ensure that I was aware of my own 'stuff' and its potential to negatively affect the research process.

Literature about effects of illness highlights a plethora of issues, not only for the ill individual but also for their formal and informal carers. I noted that research in cancer was far more accomplished than in other illnesses, which were not mentioned as frequently, and I wondered if this was due to funding or societal conceptions of the seriousness of the illness. As a practitioner, individual's despair and turmoil seemed to

relate to existential realisations. I began to wonder if these changed depending upon age and relationship to the 'patient'. Clients who have had a life threatening experience become increasingly aware of their existential existence, yet their reactions to this awareness seem to change depending upon their acceptance that their existence on earth is time limited.

Therapy can be conceptualised as aiding an individual to come to terms with loss, be it loss of self-esteem, confidence, job or hope. The therapeutic relationship looks at trying to redress the balance through meeting and reacting to, and with, the client's conscious and unconscious processes to provide interventions which are needed to enable growth and development.

6.2 WHAT?

The most logical progression of my interests and the lack of research led me to the unmet psychosocial and supportive care needs of adolescent when they have an ill parent. Due to the lack of research across various illness groups (aside from cancer), I decided to look at the broad term of non-communicable diseases (NCDs). Reading round the literature I saw that it was a massively important area of investigation which had not been evaluated for adolescent children. This increased the scope of what I could research, with my research questions dictating methodology. I decided to conduct a systematic review to ensure that I had captured all of the relevant published literature and that conceptualisations had a good grounding in the theory and frameworks of related research. This gave evidence to pragmatically investigate the research question by qualitatively understanding individual's lived experiences, which would then lead on

to quantitative research to help determine statistical associations between unmet needs, affective state, and well-being.

Within my peer group on this course I got the distinct impression that statistics were not highly favoured: this may be due to counselling psychologists valuing the client's experiences as opposed to more reductionistic methods of categorising experiences in numerical form (Woolfe, *et al.*, 2003). However, as practitioners we must adhere to the scientist practitioner model which affords an integration of science and practice (Belar, 2000).

Counselling psychologists have been stern objectors of the medical model, but have successfully integrated into medicalised organisations such as the NHS which are being increasingly measured and audited: these evaluative approaches are somewhat at odds with counselling psychology philosophy; practitioners may need to incorporate these organisational needs to remain influential within these applied fields of work. National Institute of Clinical Excellence (NICE) guidance encourages evidence based practice, this is becoming more prevalent as the need for organisational measures increase; counselling psychologists have always been advocates of practice based evidence.

Counselling psychologists are in the privileged position of being both practitioners and scientists and as such can harness the evidence gained through practice to create new knowledge. I was fortunate to formulate a research question which would allow me to pragmatically investigate an under-research area which would be of benefit to therapeutic practitioners. I see the value in both qualitative and quantitative research and as such I do not intend to close an avenue of my contributing to literature through

pledging my allegiance to a preferred methodology; I will follow the correct methodology for the research question (Newman & Benz, 1998). This thesis has given me valuable insight of conducting both qualitative and quantitative research.

As my research was on unmet needs, I began to think what my research needs were, and how I would go about fulfilling them. I read around types of methodology, and wrote queries in a research diary and discussed them with my research team. I noted that once I had one need met, another came to the fore, but knowing how others had been fulfilled gave me a route in meeting my constantly appearing research needs.

6.3 SO WHAT?

6.3.1 *Systematic Review*

The systematic review took far longer than I had thought. I was shocked at how few papers I had found on unmet needs and did toy with the idea of including papers which had implicit unmet needs included, yet I felt that this would have lost the structure which the inclusion criteria had so rigorously implemented and I was concerned that my bias as a researcher would enter the analysis. Data collection was a long and drawn out process, yet when the searches and analysis were complete I could see the value in the structured systematic review, giving me a robust starting point to base the further investigations in my thesis (Higgins & Green, 2005).

6.3.2 *IPA*

I approached schools and colleges in order to see if any of their students would like to take part in my study. I had initially aimed to recruit 12 participants, yet after a steady

stream of responses, interest and e-mails tailed off and I stopped actively recruiting when I had seven participants. This was a little disappointing, but I had become aware that my initial hopes of a larger number may have been unrealistic. IPA studies are currently averaging at 15 participants per investigation (Reid, Flowers & Larkin, 2005), however, Smith (2004) has argued that smaller numbers of participants are beneficial to gaining increased depth of analysis. This put my mind at ease that my participant numbers could be justified as being acceptable.

I was apprehensive that my interviews would potentially touch on sensitive matters, and even though it is a normal occurrence within the therapy situation, I was aware that this was not therapy. I was slightly concerned when the ethics committee asked me to include details of counselling organisations on the information sheet should the interview cause any distress. I began to wonder about the cost and benefit of doing the research. Whilst I was confident that the study could be of benefit to individuals who were experiencing illness within the family, the idea that my research may cause upset, and I was unable to put it right was difficult, went against my therapeutic grain.

In order to develop an appropriate interview relationship in which to conduct the interviews I was happy for the interviewee to go into as much or as little depth as they wanted, as such they had some control of the interview. I used my therapy skills in order to assess their level of comfort to try to ensure that the interview process was at a manageable level for the participant (Rogers, 1961). I was surprised at the emotional maturity and openness of the young adults.

The young adults were able to reflect upon their circumstances by conceptualising the intrapersonal and interpersonal effects upon both themselves and other people. Their ability to regulate their emotions and manage the depth of their narrative was humbling and made me wonder why previous research had asked third parties about the illness experience of children when they were more than able to answer the questions themselves. Upon closer reflection I believe that the previous research had skewed my conception of the adolescents maturity and resilience. Their ability to self-regulate and reflect honestly upon their situation, whilst managing their emotional responses was a humbling experience. For some of the individuals it was one of the first times they had spoken about it with someone external to the family, this makes their expression, boundaries and containment even more awe-inspiring. I began to think about the challenges which I felt when trying to get the research passed by the university ethics committee, and found that this, along with previous research, had increased my levels of trepidation. As aforementioned the adolescent's conduct within the interviews had humbled me and added to the evidence that these individuals should be given due credence and treated like an adult; mimicking the findings of the actual research. Protection from harm does not mean the same thing as protection from decision making. The concerns I felt seem to be evident in the literature surrounding parental difficulties in giving their children information for fear of emotionally damaging them (Rosenheim & Reicher, 1985). I believe my fear was also driven by an innate and professional desire not to do harm; it was an important premise for me as a 'human' and as a professional psychologist.

As a psychologist practicing in a hospital, I see many different people and listen to many different narratives, and whilst I feel confident and able to partake in a psychotherapeutic dialogue, the research interviews were vastly different. Even though I used my therapeutic skills within the session (i.e. noticing feelings, determining if an individual is in distress) I was not able to act as though I was in a therapy setting as it would not have been safe or ethical. In a therapeutic setting the practitioner has a therapeutic contract, numerous sessions and a sound assessment of their social and psychological history. Entering into any sort of therapeutic narrative within the research setting would not have been an ethically and professionally sound or defensible.

Owing to my experience of caring for a family member, which has been documented elsewhere, I wanted to ensure that I could rigorously justify and defend the themes which emerged. In order to do this I had the interview transcripts second screened and validated by an independent researcher (SF). I found it very difficult to handover the transcripts to another person, as, even though the participants were aware that they would be seen by a few other people, I felt like I was breaching confidentiality; this was a definite side effect from my practitioner ideologies. Upon handing over the information, I began to feel anxious about if our respective themes would match, or if my experience had been clouded by my personal life as I had felt that my story was echoed in the narratives of others. I was relieved when the other researcher's themes were similar to mine and even more comforted when the entire research team agreed upon the final thematic framework. The jointly created framework validated the participants' experiences as being something that four separate individuals with four different histories could determine. When discussing the themes with other members of

the team, I was a little taken aback as to how surprised they were at the plethora and richness of the participants experiences. I began to wonder if I was not quite as surprised owing to my working clinically and listening to people's struggles and their impact upon their well-being.

As I began writing up the themes I could see the complexity of their situation, and I wondered how I would be able to convey their feelings within my thematic tables and writing. I became very aware that my analysis of their experiences was based upon how well I was able to express their experience. With each transcript and quote I was able to take myself back to our respective interviews and re-experience the sense in the room, this is a technique I use in clinical supervision when thinking about client processes and is beneficial in uncovering blocks (Hawkins & Shohet, 2012). As I had a similar, yet greatly reduced, experience of looking after, and being with, an ill family member I was careful to ensure that I maintained a professional boundary by ensuring I was guided by ethical and methodological guiding principles. I wanted to ensure I was capturing their experiences and had the analysis second screened by a researcher external to the supervisory team.

I found it very difficult to write the IPA chapter with such a definite and assertive tone, as even though the research intimated that two constructs were linked, as a practitioner I am aware that real life rarely works so smoothly. As a counselling psychologist I am conscious that there is far more going on for the individual than could be captured within their narrative and that many things can have a synergic effect upon their experiential outcome, with there being no definitive answers or theoretical explanations.

6.3.3 *Quantitative study*

Ethical approval took longer than I had anticipated, and my Gantt chart dates became unrealistic. In order to keep to my schedule as far as possible, I did not go through NHS ethics, but approached institutes of higher and further education, health centres and charities in order to try to get participation. It was not an easy process as organisations took time to reply to e-mails, yet in time I managed to drum up interest in the study. I had hoped to get 138 participants, as this was the recommended participant number for power analysis (Green, 1991), but I had to stick to my time frame, meaning that recruitment had to close after just 107 questionnaires returned. I was disappointed by the lower return rate, yet I had to accept that this all that was achievable in the timeframe. Owing to participant numbers falling below Green's (1991) recommendations G*Power was used to determine if the model was powered, I was relieved that it was, as I could reasonably justify my participant numbers.

6.4 IMPLICATIONS FOR COUNSELLING PSYCHOLOGY PRACTICE

The research process has let me develop skills and think more critically. I feel confident in reading research and applying the principles to my clinical practice and as such it has affected my identity as a practitioner. I work with individuals who are inpatients on a Burns and Major Trauma Centre. As such, and as a result of the findings of this thesis I have begun asking them how we as their caring team can help them and their family more, and talk about the illness impact upon family dynamics, thus normalising its effect. I always use a curious form of enquiry whilst within a therapeutic setting, and as such, by being curious at how different members of a family react, it begins to open a

dialogue as there is no judgment assigned to any emotion or reaction. I give reference to the overarching needs (i.e. acknowledgement, information) which have been uncovered within this thesis to see what is meaningful for the ill individual. The majority of individuals state they would like more information and would like to be asked their opinions during medical and surgical consultations, thus being acknowledged. This is something which has been fed back to the medical and nursing team and is being taken on board by staff.

The research contained within this thesis has highlighted the range of psychosocial and supportive care needs that young adults who have a parent with a NCD may encounter. Counselling psychologists work in a variety of places and have the potential of aiding families who are experiencing ill health. It was very important to me that this research would not only be of interest to counselling psychologists but also benefit further research focusing on needs-based interventions.

6.5 WHERE I WOULD TAKE THE STUDY NEXT?

The contents of this thesis have contributed to knowledge surrounding unmet psychosocial and supportive care needs of adolescents who have a parent with a NCD. It has established the existence and associations of unmet needs on well-being and as such highlights the importance of meeting needs. This thesis provides such a wide range of evidence on unmet needs that further research spring boarded by this thesis, is vast.

Research looking at the mediating effects of attachment style upon type of unmet need, and the way they would prefer the need to be met (i.e. through intrapersonal or interpersonal means) would be beneficial in tailoring needs-based interventions for the

individual. As attachment is a reciprocal relationship, parental attachment style would also likely have a bearing upon type of need, as it could be argued that a securely attached individual is more able to manage and hold their distress and the distress of others, whilst being able to feel worthy enough of care, thus not pushing or pulling at family relationships (Hunter & Maunder, 2001).

The OCINI has been found to be relevant to young adults who have a parent with a NCD. Determining its applicability to younger children would be beneficial. The scale would have to be modified for language and screened for face and content validity, ensuring that it remains true to its original brief. By assessing and investigating the unmet psychosocial and supportive care needs of children it would reveal a broader overview on how unmet needs during the illness experience displays and bears influence upon individuals throughout the lifespan. This would afford health care professionals information in offering a holistic care package to families, which would have the potential of improving their current situation and future psychological and emotional wellbeing (Watson, *et al*, 2012).

6.6 HOW WELL DID I MEET MY THESIS' AIMS?

Reflecting back over the work contained within this thesis I am pleased with the research project and feel that I have managed to meet the aims of my thesis. Upon first conceptualising the thesis' aims I was aware that it was a tall order, yet I'm not certain I was aware of how much work it would be. I am pleased that I have had the courage to undertake a large and diverse piece of work and am proud of the way I have been able to time manage and to deal with obstacles that have had the potential to jeopardise my

progress. As such I believe that the thesis has not only been able to answer its initial questions and meet its aims, but is a symbolic testament of all of the work I have done and the development I have undergone during my doctoral training.

REFERENCES

** denotes references included in the systematic review.

Abrahamson, K., Durham, M., & Fox, R. (2010). Managing the unmet psychosocial and information needs of patients with cancer. *Patient Intelligence*, 2, 45-52.

Afifi, T. D., & Olson, L. N. (2005). The chilling effect in families and the pressure to conceal secrets. *Communication Monographs*, 72, 192–216.

Afifi, T. D., Olson, L. N., & Armstrong, C. (2005). The chilling effect and family secrets. *Human Communication Research*, 31, 564–598.

Afifi, T. D., McManus, T., Steuber, K., & Coho, A. (2009). Verbal avoidance and dissatisfaction in intimate conflict situations. *Human Communication Research*, 35, 357–383.

Agosto, D.E. & Hughes-Hassell, S. (2005). People, places, and questions: an investigation of the everyday life information-seeking behaviors of urban young adults. *Library and Information Science Research*, 27(2), 141-163.

Aldwin, C. (2009). *Stress, coping and development: An integrative perspective (2nd ed.)*. Guildford: Guildford Press.

Arnett, Jeffrey J. (2004). *Adolescence and Emerging Adulthood (2nd ed.)*. Upper Saddle River, NJ: Prentice-Hall, Inc.

Arora, N.K., Johnson, P., Gustatson, D.H., McTavish, F., Hawkins, R.P., & Pingree, S. (2002). Barriers to information access, perceived health competence and

- psychosocial health outcomes: test of a mediation model in a breast cancer sample. *Patient Education and Counselling*, 47(1), 37-46.
- Baer, J. (2002). Is family cohesion a risk or protective factor during adolescent development? *Journal of Marriage and Family*, 64, 668-675.
- Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review*, 84, 191–215.
- Bauman, L.J., Foster, G., Silver, E.J., Berman, R., Gamble, I., & Muchaneta, L. (2006). Caring children for their ill parents with HIV/AIDS. *Vulnerable Children and Youth Studies*, 1(1), 56-70.
- Bauman, L. J., Phuong, L., Silver, E. J., & Berman, R. (2001). Lean on me? Adjustment of children who provide support to their ill mothers with HIV/AIDS. Paper presented at the 41st Meeting of the Ambulatory Pediatrics Association, Baltimore, MD.
- Baumeister, R.F. & Leary, M.R. (1995). The need to belong: Desire for interpersonal attachments as a fundamental human motivation. *Psychological Bulletin*, 117(3), 497-529.
- Belar, C. D. (2000). Scientist-practitioner not equal to science plus practice: Boulder is bolder. *American Psychologist*, 55(2), 249-250.
- Berman, H., Cragg, C.E., & Kuenzig, L. (1988). Having a parent die of cancer: Adolescents' grief reactions. *Oncology Nursing Forum*, 15(2), 159-163.

- Berndt, T.J. & Perry, T.B. (1986). Children's perceptions of friendships as supportive relationships. *Developmental Psychology*, 22(5), 640-648.
- Bester, G. (2007). Personality development of the adolescent: Peer group versus parents. *South African Journal of Education*, 27(2), 177-190.
- Blumer, H. (1969). *Symxbolic interactionism: Perspectives and method*. Engelwood Cliffs, New Jersey: Prentice Hall.
- Boberg, E.W., Gustafson, D.H., Hawkins, R.P., Offord, K.P., Koch, C., Wen, K.-Y., Kreutz, K., & Salner, A. (2003). Assessing the unmet information, support and care delivery needs of men with prostate cancer. *Patient Education and Counseling*, 49, 233-242.
- Bonfenbrenner, U. (1979). *The Ecology of Human Development: Experiments by Nature and Design*. Cambridge, MA: Harvard University Press.
- Borton, T. (1970). *Reach, teach and touch*. McGraw Hill: London.
- Bowen, M. (1976). Theory in the practice of psychotherapy. In P. J. Guerin. (Ed.). *Family therapy*. New York: Gardner.
- Bowlby, J. (1969). *Attachment and Loss* (Vol. 1). London: Pimlico.

Brody, L. (1985). **Gender differences in emotional development: A review of theories and**

research. *Journal of Personality*, 53(2),
102-149.

Brody, L.R. (2000). The socialisation of gender differences: Display rules, infant temperament and differentiation. In A.H. Fischer (Ed.). *Social Psychological Perspectives* (pp.24-48). Cambridge: Cambridge University Press.

Buckley, I.E. (1977). *Listen to the children: Impact upon the mental health of children of a parent's catastrophic illness*. New York: Cancer Care.

Burleson, B. R. (1997). A different voice on different cultures: Illusion and reality in the study of sex differences in personal relationships. *Personal Relationships*, 4, 229-241.

Burns, N. & Groves, S.K. (1987). *The practice of nursing research conduct, critique and utilization*. Philadelphia: WB Saunders.

Burton, L., Zdaniuk, B., Schulz, R., Jackson, S., & Hirsch, C. (2003). Transitions in spousal caregiving. *The Gerontologist*, 43, 230–241.

** Chalmers, K.I., Kristjanson, L.J., Woodgate, R., Taylor-Brown, J., Nelson, F., Ramserran, S., & Dudgeon, D. (2000). Perception of the role of the school in providing information and support to adolescent children of women with breast cancer. *Journal of Advanced Nursing*, 31(6), 1430-1438.

- Chaney, J.M., Uretsky, D.L., Mullins, L.L., Doppler, M.J., Palmer, W.R., Wees, S.J., Klein, H.S., Doud, D.K., & Reiss, M.L. (1996). Differential effects of age and illness duration on pain-depression and disability depression relationships in rheumatoid arthritis. *International Journal of Rehabilitation and Health*, 2(2), 101-112.
- Cherryholmes, C. C. (1992). Notes on pragmatism and scientific realism. *Educational Researcher*, 21, 13–17.
- Cohen, J. (1988). *Statistical power analysis for the behavioural sciences (2nd ed.)*. New York: Academic Press.
- Conte, H.R. & Plutchik, R. (1995). *Ego defenses: Theory and measurement*. New York: Wiley.
- Corbin, J.M. & Strauss, A. (1988). *Unending work and care: Managing chronic illness at home*. The Jossey-Bass health series and The Jossey-Bass social and behavioral science series. San Francisco, CA: Blackwell.
- Corrigan, P.W. (2005). *On the stigma of mental illness: Practical strategies for research and social change*. Washington, DC, US: American Psychological Association.
- Daniels, J.A. (1990). Adolescent separation – individuation and family transitions. *Adolescence*, 25(97), 105-116.
- Dearden, C. & Becker, S. (2003). *Carers UK: Young carers and education*. Loughborough University: Carers UK.

- Diagnostic and statistical manual of mental disorders (DSM) (4th ed.). American Psychiatric Press.
- DiMatteo, M.R. (2004). Social support and patient adherence to medical treatment: A meta-analysis. *Health Psychology, 23*(2), 207-218.
- Dina, L.G., Borzekowski, E., & Vaughn, I.R. (2001). Adolescent cybersurfing for health information a new resource that crosses barriers. *Archives of Pediatrics & Adolescent Medicine, 155*(7), 813-817.
- Dindia, K. & Allen, M. (1992). Sex differences in self disclosure: A meta-analysis. *Psychological Bulletin, 112*(1), 106-124.
- Dixon-Woods, M., Agarwal, S., Jones, D., Young, D., & Sutton, A. (2005). Synthesising qualitative and quantitative evidence: A review of possible methods. *Journal of Health Services Research and Policy, 10*(1), 45-53.
- Doherty, W.R., Hatfield, E, Thompson, K., & Choo, P. (1994). Cultural and ethnic influences on love and attachment. *Personal Relationships, 1*, 391-398.
- Douvan, E , & Adelson, J. (1966). *The adolescent experience*. New York: Wiley.
- Driscoll, J. (2000). *Practicing clinical supervision: a reflective approach*. London: Elsevier Health Sciences.
- Duffy, M.E. (1985). Designing nursing research the qualitative quantitative debate. *Journal of Advanced Nursing, 10*(3), 225-232.

- Edwards, B. & Clarke, V. (2004). The psychological impact of a cancer diagnosis on families: The influence of family functioning and patient's illness characteristics on depression and anxiety. *Psycho-oncology*, 13(8), 562-576.
- Egger, M., Smith, G.D., & Altman, D.G. (2001). *Systematic reviews in health care: Meta-analysis in context (2nd Ed.)*. London, UK: BMJ Publishing Group.
- Elwick, H., Joseph, S., Becker, S., & Becker, F. (2010). Manual for the Adult Carer Quality of Life Questionnaire (AC-QoL). London: The Princess Royal Trust for Carers.
- Emanuel, E.J., Fairclough, L.D., Slutsman, J., & Emanuel, L.L. (2000). Understanding economic and other burdens of terminal illness: The experience of patients and their caregivers. *Annals of internal medicine*, 132(6), 451-459.
- Erikson, E.H. (1968). *Identity, Youth and Crisis*. New York: Norton & Co.
- Field, A. (2009). *Discovering statistics using SPSS (3rd ed.)*. London: Sage Publications.
- Firestone, R.W. (1983). *The fantasy bond: Structure of psychological defences*. Glendon Association: London.
- Friedlander, L.J., Reid, G.J., Shupak, N., & Cribbie, R. (2007). Social support, self-esteem, and stress as predictors of adjustment to university among first-year undergraduates. *Journal of College Student Development*, 48(3), 259-274.

- Foot, G. (1996). Needs assessment in tertiary and secondary oncology practice: a conceptual and methodological exposition [Ph.D. dissertation]. Newcastle: University of Newcastle.
- Ford, G.R., Goode, K.T., Barrett, J.J., Harrell, L.E., & Haley, W.E. (1997). Gender roles and caregiving stress: An examination of subjective appraisals of specific primary stressors in Alzheimer's caregivers. *Aging and Mental Health, 1*(2), 158-165.
- Foucault, M. (1988). *Power/knowledge: Selected interviews and other writings 1972-1977*. USA: Random House.
- Garnezy, N. (1991). Resilience in children's adaptation to negative life events and stressed environments. *Pediatric Annals, 20*, 459-466.
- Given, C., Given, B., Stommel, M., Collins, C., King, S., & Franklin, S. (1992). The Caregiver Reaction Assessment (CRA) for caregivers to persons with chronic physical and mental impairments. *Research in Nursing and Health, 15*(4), 271-283.
- Goffman, E. (1959) *The Presentation of self in everyday life*. University of Edinburgh Social Sciences Research Centre: Anchor Books.
- Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity*. (Englewood Cliffs, New Jersey: Prentice-Hall.

- Greenberg, M.T., Siegel, J.M., & Leitch, C.J. (1983). The nature and importance of attachment relationships to parents and peers during adolescence. *Journal of Youth and Adolescence*, 12(5), 373-386.
- Green, S.B. (1991). How many subjects does it take to do a regression analysis? *Multivariate Behavioural Research*, 26(3), 499-510.
- Grotevant, H.D., Thorbecke, W., & Meyer, M.L. (1982). An extension of Marcia's identity status interview into the interpersonal domain. *Journal of Youth and Adolescence*, 11(1), 33-47.
- Gursky, B. (2007). The effect of educational interventions with siblings of hospitalized children. *Journal of developmental and behavioural paediatrics*, 28(5), 392-398.
- **Handley, C., Farrell, G.A., Josephs, A., Hanke, A., & Hazelton, M. (2001). The Tasmanian children's project: The needs of children with a parent/carer with mental illness. *Australian and New Zealand Journal of Mental Health Nursing*, 10, 221-228.
- Hawkins, P. & Shohet, R. (2012). *Supervision in the helping professions (4th ed.)*. Maidenhead: Open University Press.
- Henry, J. D., & Crawford, J. R. (2005). The short-form version of the Depression Anxiety Stress Scales (DASS-21): Construct validity and normative data in a large non-clinical sample. *British Journal of Clinical Psychology*, 44, 227-239

- Higgins, J.P.T. & Green, S. (eds) (2005). *Cochrane Handbook for Systematic Reviews of Interventions 4.2.5*. Chichester, UK: John Wiley & Sons.
- Hilton, B.A. & Elfert, H. (1996). Children's experiences with mother's early breast cancer. *Cancer Practice*, 4, 96-104.
- Hindle, D. (1998). Growing up with a parent who has a chronic mental illness: one child's perspective. *Journal of Child and Family Social Work*, 3, 259-266.
- Hirst, M. (2005). Carer distress: a prospective, population-based study, *Social Science and Medicine*, 61, 3, 697-708.
- Hobfoll, S.E. (1989). Conservation of resources: A new attempt at conceptualizing stress. *American Psychologist*, 44, 513-524.
- Hobfoll, S. E. (1998). *Stress, culture, and community: The psychology and philosophy of stress*. New York: Plenum.
- Hobfoll, S. E. & Lilly, R. S. (1993). Resource conservation as a strategy for community psychology. *Journal of Community Psychology* 21, 128-148.
- Holmes, T.H. & Rahe, R.H. (1967). The social readjustment rating scale. *Journal of Psychosomatic Research*, 11, 213-218.
- Houts, P., Nezu, A.M., Maguth, N.C., & Bucher, C. (1996). The prepared family caregiver: a problem-solving approach to family caregiver education. *Patient Education Counselling*, 27, 63-73.

- Hulbert-Williams, N. J., Neal, R. D., Morrison, V., Hood, K., & Wilkinson, C. (2012). Anxiety depression and quality of life after cancer diagnosis: What psychosocial variables best predict how patients adjust. *Psycho-Oncology*, *21*(8), 857-867.
- Hunter, J.J. & Maunder, R.G. (2001). Using attachment theory to understand illness behaviour. *General Hospital Psychiatry*, *23*, 177-182.
- Hymovich, D. P. (1995). The meaning of cancer to children. *Seminars in Oncology Nursing*, *11*(1), 51-58.
- Joubert, D., Sad ghi, M.R.Z., Elliott, M. Devins, G.M., Laperri re, N., & Rodin, G. (2001). Physical sequelae and self-perceived attachment in adult survivors of childhood cancer. *Psycho-oncology*, *10*(4), 284-292.
- Keating, N.C. & Fast, J.E. (1997). Bridging policy and research in eldercare. *Cancer Journal of Aging*, *16*, S22-S41.
- **Kennedy, V.L. & Lloyd-Williams, M. (2009a). How children cope when a parent has advanced cancer. *Psycho-Oncology*, *18*, 886-892.
- **Kennedy, V.L., & Lloyd-Williams, M. (2009b). Information and communication when a parent has advanced cancer. *Journal of Affective Disorders*, *114*, 149-155.
- Kelly, A. (2010). Lost the feel for the game: Meanings and onset of onset and diagnosis of AIDS dementia for significant others. *Qualitative Health Research*, *20*(4), 531-540.

- Khan, K.S., ter Reit, G., Glanvilles, J., Sowden, A.J., & Kleijnen, J. (eds.). (2001). *Undertaking systematic reviews of research on effectiveness. CRD's guidance for those carrying out or commissioning reviews. Report Number 4 (2nd Ed.)*. York, UK: Centre for Reviews and Dissemination.
- Kline, P. (1999). *The handbook of psychological testing (2nd ed.)*. London: Routledge Press.
- Kortum, P., Edwards, C., & Kortum-Richards, R. (2008). The impact of an inaccurate internet health information in a secondary learning environment. *Journal of Medical Internet Research, 10(2)*, e17.
- **Kristjanson, L.J., Chalmers, K.I., & Woodgate, R. (2004). Information and support needs of adolescent children of women with breast cancer. *Oncology Nursing Forum, 31(1)*, 111-119.
- Kobasa, S C, (1979). Stressful life events, personality, and health: An inquiry into hardiness. *Journal of Personality and Social Psychology, 37*, 1-11.
- La Greca, A.M., Auslander, W.F., Greco, P., Spetter, D., Fisher, E.B., & Santiago, J.V. (1994). I get by with a little help from my family and friends: Adolescent's support for diabetes care. *Journal of Paediatric Psychology, 20(4)*, 449-476.
- Langeveld, J.H., Hoot, H.M., Loonen, M.C., Hazebroek-Kampschreur, A.A.& Passchier, J. (1996). A quality of life instrument for adolescents with chronic headache. *Cephalalgia, 16(3)*, 183-196.
- Lazarus, R.S. & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.

Lehr, H. & Strosberg, M. (1991). Quality improvement in health care: Is the patient still left out? *Quality Review Bulletin*, 17(10), 326-329.

Leiper, R. & Maltby, M. (2004). *The psychodynamic approach to therapeutic change*. Thousand Oaks, CA: Sage Publications.

Levit, D. (1985). Gender differences in ego defenses in adolescence: Sex roles as one way to understand the differences. *Journal of Personality and Social Psychology*, 61(6), 992-999.

Lewis, F.M., Ellison, E.S., & Woods, N.F. (1985). The impact of breast cancer on the family. *Seminars in Oncology Nursing*, 6, 193–200.

Lewis, F.M., Hammond, M.A., & Woods, N.F. (1993). The family's functioning with newly diagnosed breast cancer in the mother: the development of an explanatory model. *Journal of Behavioural Medicine*, 16, 351-370.

Llewelyn, H., Aun Ang, H., Lewis, K.E., & Al-Abdullah, A. (2009). *Oxford handbook of clinical diagnosis*. Oxford University Press: Oxford.

Lovibond, S.H. & Lovibond, P.F. (1995). *Manual for the Depression Anxiety Stress Scales*. (2nd. Ed.) Sydney: Psychology Foundation.

Maddi, S. R. (2006). Hardiness: The courage to grow from stresses. *Journal of Positive Psychology*, 1 (3), 160–168.

Maslow, A.H. (1943). A theory of human motivation. *Psychological Review*, 50(4), 370-396.

Moran, D. (2000). *Introduction to phenomenology*. London: Routledge.

Morasso, G., Capelli, M., Viterbori, P., Di Leo, S., Alberisio, A., Constantini, M., Fiore, M., Saccani, D., Zeitler, G., Verzolatto, N., Tirelli, W., Lazzari, L., Partinico, M., Borzoni, G., Savian, C., Obertino, E., Zotti, P., Ivaldi, G.P., & Henriquet, F. (1999). Psychological and symptom distress in terminal cancer patients with met and unmet needs. *Journal of Pain Symptom Management*, 17(6), 402-409.

Morris, L. W., Morris, R. G., & Britton, P. G. (1988). The relationship between marital intimacy, perceived strain, and depression in spouse caregivers of dementia sufferers. *British Journal of Medical Psychology*, 61, 231–236.

Moser, D. K., Dracup, K. A., & Marsden, C. (1993). Patients' and relatives' need for information. *Nursing Times*, 89, 52-53.

National Collaborating Centre for Methods and Tools (2006). *Critical appraisal tools to make sense of evidence*. Hamilton, ON: McMaster University. (Updated 16 December, 2011). Retrieved from <http://www.nccmt.ca/registry/view/eng/87.html>.

Newman, I., & Benz, C. R. (1998). *Qualitative-quantitative research methodology: Exploring the interactive continuum*. Carbondale: Southern Illinois University Press.

NHS Knowledge and Skills Framework (2010). Retrieved from the British Psychological Society, March 2012.

Nicholson, J., Biebel, K., Hinden, B., Henry, A., & Stier, L. (2001). *Critical issues for parents with mental illness and their families*. Rockville, MD: Center for Mental Health Services, Substance Abuse and Mental Health Services Administration.

Nijboer, C., Triemstra, M., Tempelaar, R., Sanderman, R., & Van den Bos, G.A. (1999). Determinants of caregiving experiences and mental health of partners of cancer patients. *Cancer*, 86, 577–588.

Northouse L.L. & Swain M.A. (1987). Adjustment of patients and husbands to initial impact of breast cancer. *Nursing Research*, 36, 221-225.

Oakley, A., Bendelow, G., Barnes, J., Buchanan, M., & Hussain, O.A. (1995). Health and cancer prevention: Knowledge and beliefs of children and young people. *British Medical Journal*, 310, 1029-1033.

Osborne, Jason W. (2000). Prediction in multiple regression. *Practical Assessment, Research & Evaluation*, 7(2).

** Patterson, P., Pearce, A., & Slawitschka, E. (2010). The initial development of an instrument to assess the psychosocial needs and unmet needs of young people who have a parent with cancer: piloting the offspring cancer needs instrument (OCNI). *Journal of Supportive Cancer Care*, DOI 10.1007/s00520-010-0933-7.

Palmer, R. (1969). *Hermeneutics*. Evanston IL: Northwestern University Press.

- Palmer, N., Wilson-Smith, D., & Hulbert-Williams, N.J. Exploring adjustment in young children of cancer patients: A pilot qualitative study. *In review: Social Science & Medicine.*
- Pendley, J.S., Kasmien, L.J., Miller, D.L., Donze, J., Swenson, C., & Reeves, G. (2002). Peer and family support in children and adolescents with type 1 diabetes. *Journal of Paediatric Psychology, 27*(5), 429-438.
- Perls, F. (1969). *Gestalt therapy verbatim*. London, Routledge.
- Petronio, S. (2002). *Boundaries of privacy: Dialectics of disclosure*. Albany, NY: SUNY Press.
- Petticrew, M. & Roberts, H. (2006). *Systematic reviews in the social sciences: A practical guide*. Oxford: Blackwell Publishing.
- Piko, B.F., Keresztes, N., & Pluhar, Z.F. (2006). Aggressive behavior and psychosocial health among children. *Personality and Individual Differences, 40*, 885-895.
- Press, N., Fishman, J.R., & Koenig, B.A. (2000). Collective fear, individualized risk: The social and cultural context of genetic testing for breast cancer. *Nursing Ethics, 7*(3), 237-249.
- Prinstein, M.J., & Dodge, K.A. (2008). *Understanding peer influence in children and adolescence*. Guildford: Guildford Press.
- Reichardt, C. S., & Rallis, S. F. (Eds.). (1994). *The qualitative-quantitative debate: New perspectives*. San Francisco: Jossey-Bass.

- Reid, K., Flowers, P. & Larkin, M. (2005). Exploring lived experience. *The Psychologist*, 18(1), 20-23.
- Ricoeur, P. (1970). *Freud and philosophy*. New Haven, CT: Yale University Press.
- Rogers, C. (1961). *On becoming a person: A therapist's view of psychotherapy*. Boston, New York: Constable.
- Rolf, G., Freshwater, D. & Jasper, M. (2001). *Critical reflection for nursing and the helping professions: a user's guide*. Palgrave Macmillan: Basingstoke.
- Roloff, M. E., & Ifert, D. E. (2000). *Conflict management through avoidance: Withholding complaints, suppressing arguments, and declaring topics taboo*. In S. Petronio (Ed.). *Balancing the secrets of private disclosures* (pp.151–163). Mahwah, NJ: Lawrence Erlbaum.
- Rosenheim, E. & Reicher, R. (1985). Informing children about a parent's terminal illness. *Journal of Child Psychology and Psychiatry*, 26(6), 995-998.
- Rosnow, R.L. & Rosenthal, R. (1989). Statistical procedures and the justification of knowledge in psychological science. *American Psychologist*, 44(10), 1276-1284.
- Rossi, J. S. (1990). Statistical power of psychological research: What have we gained in 20 years? *Journal of Consulting and Clinical Psychology*, 58, 646-656.
- Ryle, A. (1990). *Cognitive Analytic Therapy: Active Participation in Change*. Chichester: John Wiley & Sons.

- Sanson-Fisher, R., Girgis, A., Boyes, A., Bonevski, B., Burton, L., & Cook, P. (2000). The unmet supportive care needs of patients with cancer. *Cancer, 88*, 226–237.
- Savundranayagam, M.Y., Montgomery, R.J.V., & Kosloski, K. (2011). Dimensional analysis of caregiver burden among spouses and adult children. *The Gerontologist, 51*(3), 321-331.
- Scheier, M.F. & Carver, C.S. (1992). Effects of optimism on psychological and physical well-being: Theoretical overview and empirical update. *Cognitive Therapy and Research, 16*, 201–228.
- Schore, A.N. (2001). Attachment and the regulation of the right brain. *Attachment & Human Development, 2*, 23–47.
- Schubart, J.R., Kinzie, M.B., & Farace, E. (2008). Caring for the brain tumor patient: Family caregiver burden and unmet needs. *Neurological Oncology, 10*(1), 61-72.
- Schwarzer, R. & Leppin, A. (1991). Social support and health: A theoretical and empirical overview. *Journal of Social and Personal Relationships, 8*, 99–127.
- Sharpe, L., Butow, P., Smith, C., McConnell, D., & Clarke, S. (2005). The relationship between available support, unmet needs and caregiver burden in patients with advanced cancer and their carers. *Psycho-Oncology, 14*(2), 102-114.
- Siegel, B. & Silverstein, S. (2001). *Growing up with a developmentally disabled sibling*. Da Capo Press: England.

- Smith, J. A. (1983). Quantitative versus qualitative research: An attempt to clarify the issue. *Educational Researcher*, 12, 6–13.
- Smith, J.A. (2003). *Qualitative psychology: A practical guide to research methods*. London: Sage.
- Smith, J.A. & Osborn, M. (2003). Interpretative phenomenological analysis. In JA Smith (ed.). *Qualitative Psychology*. London: Sage.
- Smith, J.A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, 1, 39–54.
- Smith, J.A. & Eatough, V. (2007) Interpretative Phenomenological Analysis. In E. Lyons, & A. Coyle (Ed.), *Analysing qualitative data in psychology* (pp.35-50). London: Sage.
- Smith, J.A., Harre, R., & van Langenhove, L. (1995). *Rethinking Psychology*. London: Routledge.
- Smith, J., Jarman, M., & Osborn, M. (1999). Doing interpretative phenomenological analysis. In M. Murray & K. Chamberlain *Qualitative health psychology: Theories and methods* (pp, 218-240). London: Sage.
- Sroufe, A.J., Egeland, B., Carlson, E., & Collins, A.W. (2005). *The Development of the Person: The Minnesota Study of Risk and Adaptation from Birth to Adulthood*. Minnesota: University of Minnesota Press.

- Stiffler, D., Barada, B., Hosei, B., & Haase, J. (2008). When mom has breast cancer: an adolescent daughter's experiences of being parented. *Oncology Nursing Forum*, 35(6), 933-940.
- Stone, R., Cafferata, G.L., & Sangl, J. (1987). Caregivers of the frail elderly: A national profile. *Gerontologist*, 27, 616-626.
- Soothill, K., Morris, S.M., Harman, J.C., Francis, B., Thomas, C., & McIlmurray, M.B. (2001). Informal carers of cancer patients: what are their unmet psychosocial needs? *Health and Social Care Community*, 9(6), 464-475.
- Storey, L. (2007). Doing interpretative phenomenological analysis. In E. Lyons & A. Coyle (Eds.), *Analysing qualitative data in psychology* (pp -). London: Sage.
- Tabachnick, B.G. & Fidell, L.S. (2001). Using multivariate statistics. Allyn and Bacon: University of Michigan Press.
- Taylor, R.M., Gibson, F., & Franck, L.S. (2008). The experience of living with a chronic illness during adolescence: a critical review of the literature. *Journal of Clinical Nursing*, 17(23), 3083-3091.
- Taylor, R.M., Franck, L.S., Dhawan, A., & Gibson, F. (2010). The stories of young people living with a liver transplant. *Qualitative Health Research*, 20(8), 1076-1090.

- **Thomas, N., Stainton, T., Jackson, S., Cheung, W.Y., Doubtfire, S., & Webb, A. (2003). 'Your friends don't understand': Invisibility and unmet need in the lives of 'young carers'. *Child and Family Social Work*, 8, 35-46.
- Vangelisti, A. L. & Caughlin, J. P. (1997). Revealing family secrets: The influence of topic, function, and relationship. *Journal of Social and Personal Relationships*, 14, 679-705.
- Vygotsky, L. (1978). *Mind in society: development of higher psychological processes*. Harvard University Press.
- Watson, E., Rose, P., Neal, R., Hulbert-Williams, N., Donnolly, P., Hubbard, G., Elliot, J., Campbell, C., Weller, D., & Wilkinson, C. (2012). Personalised cancer follow-up: risk stratification, needs assessment or both? *British Journal of Cancer*, 106, 1-5.
- Welch, A.S., Wadsworth, M.E., & Compas, B.E. (1996). Adjustment of children and adolescents to parental cancer. *Cancer*, 77, 1409-1418.
- Wellisch, D.K. (1981). Family relationships of the mastectomy patient: Interactions with the spouse and children. *Israeli Journal of Medical Science*, 17, 993-996.
- Williams, K. & McGillicuddy De-Lisi, A. (2000). Coping Strategies in Adolescents. *Journal of Applied Developmental Psychology*, 20(4), 537-549.
- Willig, C. (2001). *Introducing qualitative research in psychology: Adventures in theory and method*. Buckingham: Open University Press.

- Woolfe, R., Strawbridge, S., & Dryden, W. (2003). *Handbook of Counselling Psychology*. (3rd ed.). London: Sage.
- World Health Organization. (2011). Non communicable diseases: country profiles 2011. Retrieved January 8, 2012, from <http://www.who.int/publications/en/>
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health, 15*(2), 215-228.
- Zalenski, R.J. & Raspa, R. (2006). Maslow's Hierarchy of Needs: A Framework for Achieving Human Potential in Hospice. *Journal of Palliative Care, 9*(5), 1120-1127.
- Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *Gerontologist, 20*, 649–655.