

COPING WITH CANCER: THE ADOLESCENT EXPERIENCE.

Submitted by
Tracy Till.
BN, Grad Cert Nurs (Adv Paeds), Grad Cert Nurs (Paed Onc).

A thesis submitted in total fulfillment of the requirements of the degree of
Masters of Nursing (Research)

School of Nursing
Faculty of Health Sciences.



Australian Catholic University
Research Services
Locked Bag 4115,
Fitzroy, Victoria 3065
Australia

Date of Submission : 16/02/2004

Statement of Sources.

This thesis contains no material published elsewhere or extracted in whole or in part from a thesis by which I have qualified for or been awarded another degree or diploma.

No other person's work has been used without due acknowledgment in the main text of the thesis.

This thesis has not been submitted for the award of any degree or diploma in any other tertiary institution.

All research procedures reported in this thesis received the approval of the relevant Ethics/Safety Committees.

Signed: _____ Tracy Till. 16/02/2004

Acknowledgements

There are many people who played an important role in the development of this thesis. Firstly I would like to mention and thank the adolescents and their families involved in this process.

I would also like to express my gratitude to my lecturers Karen Flowers, Paula Schulz, and Anthony Tuckett for their support and guidance throughout the development of this thesis.

I would also like to thank Dr Liane Lockwood for her support during the RCH project and for acquiring funding from Queensland Health for the Project.

Finally I would like to thank my husband and my family for their support throughout this process.

Abstract

Adolescence is the period of physical and emotional development from childhood to adulthood. As an adolescent develops they struggle with many issues including developing independence from their parents, embracing peer culture, an increase in the importance of body image and the development of sexual, vocational, and moral identity. The diagnosis and treatment for cancer can interfere with the adolescent meeting these goals, and subsequently cause the experience of adolescence to be more difficult.

The aim of this study was to identify how adolescents with cancer cope with their situation. The objectives were to determine the resources adolescents utilise to cope with their experience, and the coping strategies adolescents use to cope with their experience. A thorough literature review identified that there had previously been only limited research with adolescents with cancer. In particular there had been very few qualitative studies investigating the specific coping strategies used by adolescents with cancer, with no such research being undertaken in Queensland.

This study was conducted under the epistemological stance of constructionism. Meaning was constructed for this study of adolescents with cancer through the use of grounded theory methods, and secondary analysis of data. Interviews were collected by the researcher for a project at the Royal Children's Hospital. Using grounded theory methods, seven of the interviews were analysed. In the process of developing a central category, Schatzman's Dimensional Matrix was used to assign codes into context, processes, consequences, and conditions, under the central category of "conquering the cancer experience".

The experience of diagnosis and treatment for cancer was difficult for these adolescents, however they ultimately coped and became stronger as a result of their experience. The key findings of this study identified that adolescents were able to cope with their experience. These findings were discussed in relation to factors which enhanced their coping, factors which influenced their ability to cope and how the experience changed the adolescent. Recommendations were also made with the aim of improving the experience of adolescents undergoing treatment for cancer in Queensland. Through the implementation of the recommendations of this study, hopefully the journey of adolescents with cancer can be made easier.

Abbreviations

ABS	The Australian Bureau of Statistics
ACU	Australian Catholic University
ALL	Acute Lymphoblastic Leukaemia
BMT	Bone Marrow Transplant
HREC	Human Research Ethics Committee
QNC	Queensland Nursing Council
RCH	Royal Children's Hospital – Brisbane, Queensland
SIOP	Soci�t� Internationale D'Oncologie P�ditrique (International Society of Paediatric Oncology)
SWCPIPOS	SIOP working committee on psychosocial issues in pediatric oncology
TCU	Teenage Cancer Unit
TAT	Thematic Apperception Test
UK	United Kingdom
USA	United States of America
WHO	World Health Organization

TABLE OF CONTENTS

Statement of Sources	ii
Acknowledgements.	iii
Abstract	iv
Abbreviations	v
List of Tables	ix
List of Figures	x
 CHAPTER 1: INTRODUCTION	 1
Introduction	1
Aims and Research Objective	1
Background	2
Adolescence	2
Cancer in the Adolescent	3
The effects of treatment for cancer on the adolescent	6
Case study	6
Unique issues of adolescents with cancer	7
Psychosocial Development	8
Social development	8
Body image	9
Sexuality	9
Emerging independence	9
Career path	10
Informational requirements	10
Impact on families	11
Cancer support groups	12
Significance	12
Organisation of Thesis	13
Conclusion	14
 CHAPTER 2: LITERATURE REVIEW	 15
Introduction	15
Informational Needs	16
Relationships with Health Team	18
Disruption in Peer Relationships	20
Sexuality	22
School Disruption and Future Goals	24
Summary	26
 CHAPTER 3: METHODOLOGY	 27
Introduction	27
Methodology	28
Qualitative Research	29
Grounded Theory	30
Grounded Theory Techniques	31
Constant comparison	32
Sampling	32
Royal Children's Hospital research project	33
Ethical considerations	35
Theoretical sampling	35

A Grounded Theory Approach to Analysis	38
Open Coding	39
Microscopic Analysis	39
Axial Coding	43
Memo Writing	45
Selective Coding	46
Discovery a central category	46
Schatzman's dimensional matrix	47
Theoretical Sampling	50
Conclusion	50
CHAPTER 4: RESULTS	52
Introduction	52
Conquering the Cancer Experience	52
Context of Conquering the Cancer Experience	53
Feeling Different	53
Being treated differently by friends	53
When at home	54
Being restricted	55
Losing Control	56
Making decisions	57
Feeling trapped	58
Feeling in the dark	60
Worrying	61
Feeling exhausted	62
Conditions of Conquering the Cancer Experience	63
Hospitalisation	63
Distance from home	63
Age of others in hospital	64
Food	65
Available resources	66
Social Supports	67
Parents and family	67
Peers	68
Therapeutic relationships	70
Processes of Conquering the Cancer Experience	73
Escaping	73
Not thinking about it	73
Play	75
Gaining Control	76
Keeping informed	76
Restructuring school programs	78
Seeking New Friends	79
Socialising in hospital	79
Attending support groups	80
Consequences of Conquering the Cancer Experience	80
Appreciating Life	81
Being healthier	81
Feeling stronger	82
Developing New Career Pathways	83
Conclusion	84

CHAPTER 5: DISCUSSION/CONCLUSION	85
Introduction	85
Coping and Stress	86
Factors Influencing Coping	89
Relationships with Staff	89
Developing relationships	89
Communication	92
Care related decision making	93
Hospital Environment	95
Room sharing	95
Distraction strategies	96
School	98
Community Factors	99
Distance from treatment centre	99
Family supports	102
Peer supports	103
Physiological Factors	105
Caloric requirements	105
Fatigue	106
Life Changes	108
Feeling different	108
Risk taking behaviour	109
Self perception	110
Limitations	111
Implications for Practice	111
Recommendations for Health Professionals	112
Recommendations for Further Research	114
Recommendations for Hospital Planners	114
Final Comments	116
Appendix 1: RCH Ethics Approval	117
Appendix 2: ACU HREC Approval	119
Appendix 3: Interview Schedule for RCH project	121
Appendix 4: Further Verbatim Quotations	122
Reference List	128
Personal Communication	135

List of Tables

Table	Title	Page
Table 1.1	Support groups available for adolescents with cancer in Queensland	11
Table 3.1	Inclusion Criteria for RCH Project	34
Table 3.2	Theoretical Sampling Guide	36
Table 3.3	Participants	38
Table 3.4	Developing Concepts	41
Table 3.5	Developing Categories	42
Table 3.6	Combining Sub-categories into Categories	44
Table 3.7	Memoing	46
Table 3.8	“Conquering the cancer experience”: Categories and Subcategories	49
Table 5.1	Folkman’s et al.’s eight coping strategies	88
Table 5.2	Price comparisons for distraction tools	97
Table 5.3	Recommendations for health professionals	112
Table 5.4	Recommendations for further research	113
Table 5.5	Recommendations for hospital planners	114

List of Figures.

Figure	Title	Page
Figure 1.1	Incidence of cancer by type in adolescence	4
Figure 3.1	Matrix for explanatory paradigm	48
Figure 5.1	Lazarus and Launier's stress appraised event theory	86

CHAPTER 1: INTRODUCTION

INTRODUCTION

Adolescence is the period of development when a child becomes an adult. There are many tasks an adolescent achieves in their development to adulthood. These include developing independence from their parents, developing relationships, and one of the most difficult, choosing a career path. The diagnosis of and treatment for cancer is a difficult time for individuals and their families, and is compounded by these challenges of adolescence. To help adolescents cope effectively with their experience of cancer, health professionals need insight into the challenges that these adolescents endure and an understanding of what resources each adolescent needs.

AIM AND RESEARCH OBJECTIVES

The initial aim of this study was to investigate how adolescents with cancer manage their situation. In accordance with grounded theory methods no specific hypothesis or research question was formulated for the study prior to the analysis, the central problem or concern would emerge from the data. Initially the analysis investigated the substantive area of adolescents with cancer who had been hospitalised. This investigation attempted to identify the central problem or concern and identify and describe the basic social processes used to address it. Analysis of the data revealed the central concern to be that the adolescents felt different because they were diagnosed and treated for cancer. The analysis then focused on identifying how the adolescents with cancer coped with their situation. Specific objectives were then developed to identify 1) the strategies that adolescents use to cope with their experience, and 2) the resources adolescents utilise to cope with their experience.

BACKGROUND

This study was set in the context of adolescence and the diagnosis and treatment of cancer. These aspects of the context are discussed in this chapter to establish the significance of the study. The developmental aspects of adolescence will be discussed, leading to an overview of the unique requirements of adolescents with cancer.

Adolescence

The WHO defines adolescence as the stage of development between the ages of ten and 19 years (SERG, n.d.). The developmental stage of adolescence is described as the transition between childhood and adulthood. There are a number of developmental tasks which are achieved through this process including, developing independence from parents, an embracement of peer culture, an increase in the importance of body image, and the development of sexual, vocational, and moral identity (Brook, 1993). There are also physical and cognitive aspects of development which are significant at this time.

Individuals develop their initial career path during adolescence and many find this a very difficult part of their lives. In 1998, there were 258 587 adolescents in Queensland, 71 percent of them completed grade 12 (ABS, 2000). Approximately 50 percent of all older adolescents were involved in some form of higher education. The unemployment rate in 1998 was approximately 15 percent for young people (Dusseldorf Skills Forum, 1998). Moving through adulthood many individuals change their initial career path for various reasons. The diagnosis of cancer in adolescence may lead the adolescent to change their initial career path due to their diagnosis and treatment.

According to Neinstein (1996), a child physically becomes an adolescent when they begin to develop secondary sexual characteristics, and they are considered adult

when they stop growing. Development during adolescence may be divided into three phases, early adolescence (ten to 13 years), middle adolescence (14 to 17 years), and late adolescence (17 to 21 years) (Neinstein). As an adolescent develops they pass through each of these phases at their own pace onto adulthood. Cognitive development is also a key feature of adolescence. According to the information-processing approach to cognitive development, children and adolescents develop their ability to process information gradually building their abilities of memory and thinking (Santrock, 2004). Adolescents are able to process information differently to children because of their structural and functional capacity. The adolescent's brain has developed so that it is physically able to function at a higher level and they are able to utilise this higher function (Seifert & Hoffnung, 2000). Throughout adolescence these abilities improve. An adolescent cannot conceptualise as much information in early adolescence as in late adolescence. An adolescent's ability to process information may impact on their ability to cope with their situation.

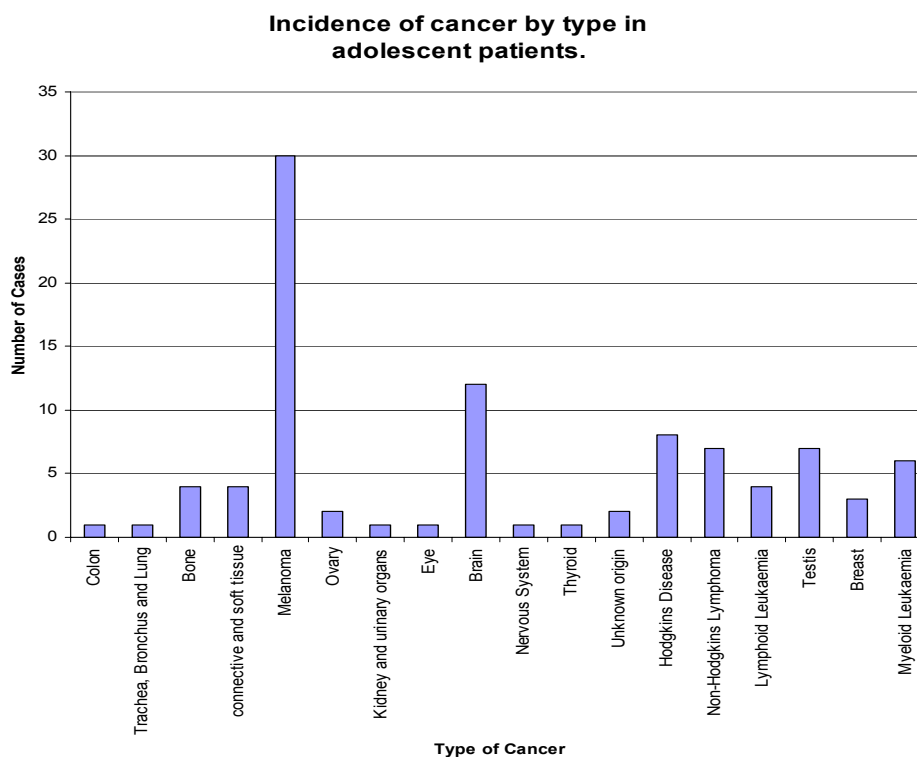
Each adolescent differs in their responses to the demands and opportunities of growing up. Biological, social, emotional, and intellectual growth may occur at different times and rates throughout adolescence. The diagnosis of cancer has the potential to greatly affect each of these aspects of adolescence, and present further challenges to the young person.

Cancer in the Adolescent.

During 1998, 15 544 Queensland residents were diagnosed with cancer: 80 were younger than ten, and 95 were aged between ten and 19. The incidence of cancer in adolescents is 37 per 100 000. Figure 1.1 (page 4) shows the incidence of the different forms of cancer in adolescence. During 1998, 24 adolescents with cancer died from their disease (Queensland Cancer Registry, 2000). Queensland adolescents diagnosed with cancer are usually treated in paediatric or adult oncology wards

throughout Queensland. The data displayed in Figure 1.1 shows a higher incidence of melanoma than other types of cancer, possibly related to Queensland's geographical position. Following melanoma, brain tumours, leukaemias and lymphomas are common in adolescence which correlates with data from the UK where leukaemia and lymphoma were the most common cancers in adolescence (Lewis, 1996).

Figure 1.1 – Incidence of cancer by type in adolescent patients



(Queensland Cancer Registry, 2000)

Cancer treatment in adolescents is similar to that of adults and is often part of national and international research studies. The treatment may include chemotherapy, radiation therapy and/or surgery (Pizzo & Poplack, 2002; Pinkerton, Plowman & Pieters, 2004; Gibson & Evans, 1999; Pinkerton, Michalski, & Veys, 1999; Whelan, 2003). These treatment regimes are commonly known as protocols. The protocol is a guide for the type of treatment to be used. The main aim of treatment is to administer enough chemotherapy or radiation to cure the cancer while minimising effects of

treatment. These effects can be debilitating and occasionally fatal (Weiner & Cairo, 2002). The specific medical treatment for all cancers should follow the recommended protocols for that disease and is generally not age related. However, psychosocial aspects of care should be provided in an age related manner (Lewis, 1996).

Brisbane has two major paediatric oncology units, which service Queensland, northern New South Wales and occasionally Papua New Guinea. Some families travel from the Northern Territory for their child's treatment if they have family in or around Brisbane. Annually the Royal Children's Hospital in Brisbane cares for approximately 100 children with cancer and their families. Eighty percent of these families live outside Brisbane and are required to travel there for their child's treatment. In 2003, there were 104 newly diagnosed paediatric patients; of which 81 lived outside of Brisbane (Kennedy, Personal Communication, September 23, 2004). Queensland is a state of geographical vastness that often requires patients to travel significant distances for treatment, increasing their isolation during a time when social support is important. The issue of distance is not limited to Queensland as other Australian states and territories have distance challenges, in particular Western Australia, the Northern Territory and South Australia.

Lewis (1996) identified a significant increase in the long-term survival rates of patients when treatment was coordinated in a major children's cancer care hospital or unit. This is due to the specific oncology focus of the multi-disciplinary team and the supportive care facilities available. There is no equivalent data currently available on adolescents who have cancer, however it is likely that a similar increase in survival rates would apply in this age group if treatment is provided by a specialist multi-disciplinary team.

The effect of treatment for cancer on an adolescent

Due to the intensity of treatment most adolescents with cancer lose their hair, lose or gain weight, require frequent injections, miss large portions of school, and frequently spend long periods of time in hospital. All adolescents with cancer from rural settings spend at least the first six weeks of treatment at a major oncology centre far from their home. They are required to return for treatment every two weeks for the next six months, after which they require monthly outpatient visits which can be provided closer to home. The following case study provides an illustration of a typical treatment course for an adolescent with cancer.

Case Study

John is a fifteen-year-old boy who was diagnosed with acute lymphoblastic leukaemia (ALL) seven months ago. He was commenced on the Australian New Zealand children's cancer study group (ANZCCSG) study VII ALL protocol. The ANZCCSG study VII ALL protocol is a plan for treatment that most children and adolescents will receive in Australia. This protocol involves six to 12 months of very intensive intravenous, oral, sub-cutaneous and intramuscular chemotherapy, requiring him to stay in Brisbane for a majority of this time, followed by 12 to 18 months of less intensive chemotherapy, monthly intravenous injections and daily tablets. His home is two and half hours drive from Brisbane.

John's chemotherapy protocol is divided into five phases, which involves two years of treatment. In the 'Study VII protocol' individuals are divided into two treatment groups depending upon age at diagnosis and clinical features such as white cell count and cytogenetics of the leukaemia cells. John was placed in the high risk group because of his age. Any person who develops ALL after the age of ten is at a higher risk of having a more aggressive form of the disease than children under ten, and therefore need more intensive treatment to achieve cure (Griffin, 2003).

John's hair started to fall out at about week three of treatment. His hair has not grown back properly in the six months since that time. He is currently receiving a less intensive phase of treatment for eight weeks and his hair should grow a little before he starts the last intensive cycle of chemotherapy. He will then commence maintenance therapy, where he is required to take chemotherapy tablets daily, and receive monthly intravenous chemotherapy either in Brisbane or his local hospital if possible. John has had 37 admissions to hospital in Brisbane and 11 general anaesthetics in the last seven months. His admissions to hospital have varied in length from one day (for outpatient chemotherapy) to two weeks. During his extended admission his mother stayed with him and provided support emotionally as well as with his activities of daily living. When he is at home he rarely goes to school due to fatigue from the chemotherapy. John has had wide fluctuations in his weight since he became unwell. Prior to diagnosis John's weight dropped by eight kilograms to 47 kilograms. In the first eight weeks of treatment he was given an oral steroid which made him hungry and he put on 15 kilograms. Since he has stopped the steroid he has lost 12 kilograms and suffers from anorexia. John doesn't like the food provided in the hospital and so his mother prepares food to encourage him to eat and not lose any more weight. ALL is the most common childhood cancer, although from the available data in the adolescent age range, melanoma is more common (see Fig 1.1, page 4) (Queensland Cancer Registry, 2000). The chemotherapy John receives is very intensive, as ALL is a very aggressive cancer, which means he is at a high risk of relapse of his disease and death.

Unique issues of adolescents with cancer

While adolescents with cancer have many of the same needs as other adolescents, there are some issues which are unique to them as they face the challenges of a life threatening illness. The following issues were identified in the literature on this topic, psychosocial development (including social needs, body image, sexuality

issues, and emerging independence issues), career path, informational requirements, the impact on their family, and support groups. The impact of these issues is different from those of their 'healthy' peers and so impact on the ability of an adolescent with cancer to cope with their illness and adolescence. Discussion of how these issues impact on their lives highlights the challenges faced by adolescents diagnosed and treated for cancer and contributes to the context for the study.

Psychosocial Development

The diagnosis of cancer can impact on many areas of an adolescents' development including their psychosocial development. The areas of psychosocial development which can be affected by the diagnosis of cancer include social development, body image, sexuality and emerging independence. The impact of diagnosis on each of these areas will be discussed.

Social Development

A large part of an adolescent's socialisation usually occurs in school, and this can be disrupted by a diagnosis of cancer (Hampson, 2000). McCallum and Carr-Gregg (1987) stressed that the problem of peer rejection in adolescence had been under-estimated in the past. As an adolescent develops socially, peers become their main focus, rather than parents and family. An adolescent's self-esteem is affected by peer acceptance (Roberts, Turney, & Knowles, 1998). Rudin, Martinson and Gilliss (1988), investigating the psychosocial concerns of adolescents with cancer, found that peer relationships either strengthened or weakened with the diagnosis of cancer. Therefore, a lengthy period of separation from peers during cancer treatment can add to the adolescent's sense of isolation, which may in turn affect their ability to develop and maintain a healthy social network.

Body Image

The adolescent with cancer has to deal with physical changes as a result of their treatment in addition to the usual developmental changes, which can lead to the adolescent with cancer having trouble maintaining a positive body image (Carr-Gregg & White, 1987). Hair loss, weight gain, 'moon-faced' appearance and acne are some of the issues which may have a negative impact on an adolescent with cancer when they are developing self esteem, body image and sexual identity. The establishment of body image involves the adolescent integrating their fantasy of an ideal body and their real body image (Carr-Gregg & White). As they are developing, adolescents need to feel similar to their peers in appearance and lifestyle. Treatment can affect their ability to do this. Self-consciousness develops in adolescence and may be exaggerated due to the physical changes caused by their treatment (Roberts, et al., 1998).

Sexuality

Adolescents' developing sexuality can range from conversation to sexual intercourse (Carr-Gregg & White, 1987). Sexual awareness occurs as the adolescent develops towards physical maturity (Whyte & Smith, 1997). Cancer treatments can cause gonadal damage and affect future fertility, and adolescents may feel uncomfortable talking about sexual issues with healthcare workers (Whyte & Smith). Roberts et al. (1998) state that there must be careful discussion with adolescents about their fertility so that they are able to understand and make safe informed choices for themselves.

Emerging Independence

The diagnosis of cancer in an adolescent may impede development of independence from their parents and cause disruption within the family (McCallum & Carr-Gregg, 1987). Adolescence is a time when a young person is just beginning to develop a sense of independence. Independence can be lost for an adolescent with

cancer as they are often dependent on their parents for transport to clinics and support during painful treatments. This loss of independence can be compounded by protective actions of the adolescent's parents as they may feel a need to take control of the situation. Similarly, the structure of modern treatment regimes shifts the focus of the adolescent's life from their home and peers to the hospital (Carr-Gregg & White, 1987). Adolescents may display hostility as a way of rebelling against this unwanted dependency (Roberts et al., 1998). Adolescents with cancer may try to find ways of exerting their independence as a coping strategy (Folkman, Lazarus, Dunkel-Schetter, DeLongis & Gruen, 1986).

Career Path

Most adolescents will develop life goals and a plan of their career path. Cancer treatment may influence an adolescent's career path and life goals. The adolescent may feel that they are limited in their life choices by their cancer and develop feelings of futility and despair. The adolescent may feel that the cancer limits their opportunities for career development or they may set themselves unrealistic goals at school, and become disappointed when they are not able to achieve them (Perrin & Gerrity, 1984). Stern, Norman and Zevon (1993) investigated social support, and found that older adolescents with cancer had a better understanding of what they wanted to do for a career than younger adolescents with cancer. This is probably due to their developmental stage and their ability to process information which could impact on their ability to understand long term consequences.

Informational requirements

Adolescents with cancer require information about their diagnosis, treatment and side effects to feel control over their situation. They have similar informational needs to adult cancer patients due to their cognitive development. Adolescents understand abstract and complex concepts and feel empowered if they are given the

opportunity to have access to their own records, or allowed to choose options if they exist (Hampson, 2000). Empowering patients through support and information helps them to develop improved coping mechanisms (Whyte & Smith, 1997).

Timing and delivery methods can affect the way an adolescent is able to understand information given to them. An awareness of how the adolescent is feeling is important because if they are feeling unwell or is in an unfamiliar environment, they may find it difficult to understand, or be overwhelmed by difficult concepts. They may feel pressured and therefore not absorb the information given to them (Woodgate, 1998). Therefore, adolescents require timely information provided when they are able to absorb it.

Impact on the family

Family dynamics can be compromised when an adolescent is diagnosed with cancer because it can cause changes in the roles of family members. The adolescent may not be able to fulfill their usual roles and siblings may need to assume aspects of adult roles (Roberts et al., 1998). The family's finances may be disrupted due to the loss of one parent's income because they are required to care for the adolescent. This loss of income can affect the family's lifestyle. The change in family dynamics can also impact on the adolescent's siblings and they may be at a higher risk of psychosocial problems (Roberts et al.).

Parents' reactions to their adolescent's cancer diagnosis differs between families, depending on their coping skills. Families who have dealt with an adolescent with cancer showed lower levels of coping than a comparatively normal sample of families with well adolescents (Greenberg, Kazak & Meadows, 1989). Birenbaum (1990) showed that parents who have poor coping skills may become over protective of their adolescent with cancer. It has also been identified that hopelessness in a child with cancer maybe related to their parent's coping mechanisms (Greenberg et al.).

Cancer support groups

Currently in Queensland there are four groups which provide support specifically for adolescents with cancer. These are Camp Quality, Leukaemia Foundation, Seize the Day (Cancer Fund), and Canteen. These groups are available for any adolescent who has cancer. A summary of services and facilities available through these groups is displayed in Table 1.1. Also included in this table are support groups which provide accommodation, monetary and emotional support for parents and families of people with cancer. Support groups have been identified by Yalom (1995) as important because they offer an opportunity for hope, a sense of normality, sharing information and the opportunity to learn, as well as an opportunity of modelling appropriate behaviours.

Table 1.1 - Support groups available for adolescents with cancer in Queensland

Name	Age of participants	Support available
CanTEEN	11 years to 25 years	Camps, peer support, grief counseling, Sibling involvement
Seize the day	11 years to 22 years	Camps, peer support, monthly meetings, and newsletters
Leukaemia Foundation	All Ages	Education and Support Programs, Counselling Liaising with community organisations, Accommodation, Financial and practical assistance
Children's Leukaemia and Cancer Society	All Ages	Counselling, Accommodation, Recreation activities, Support, Drop in centre, Transport and Financial support.
Queensland Cancer Fund	All Ages	Educational material, counseling, Look good feel better programs.

(Sources: J. Kanakis & B. Hartigan, personal communication, August 11, 2001; L. Keen, personal communication, August 7, 2001; CanTEEN, n.d.; QLD Cancer Fund, 2004; CLCS, 2004)

SIGNIFICANCE

The diagnosis and treatment for cancer impacts on the adolescent and their family. Cancer impacts on the adolescent's development causing changes and restrictions. However, with all of these challenges adolescents can be cured of their disease and seem to be able to cope with their experience. Research into the impact of these changes and restrictions is important because it helps to increase the knowledge

and support provided to adolescents with cancer. The following literature review displays that there is limited research into adolescents with cancer.

This research study aimed to identify how adolescents with cancer cope with their situation, the resources adolescents utilise to cope with their experience and the coping strategies adolescents use to cope with their experience. This research will provide staff caring for adolescents with cancer with knowledge to better help these adolescents enhance their coping strategies.

ORGANISATION OF THE THESIS

This thesis has been divided into five chapters. This introductory chapter presented the aims and objectives and explored the context of the study. In particular, it reviewed features of adolescent development and described the experience of being diagnosed and treated for cancer. It also established the significance of the study. The second chapter presents the literature review, which confirms that there has been very limited research into adolescents with cancer. However, the research which has been conducted identifies many areas where adolescents with cancer are unique from their peers. Most of the studies reviewed in the second chapter were from the UK and the USA and so may not be applicable to the Australian context. The literature reviewed in this chapter was used according to grounded theory principles as a means of justifying the need for the study.

The third chapter describes the methodological approach of the research and research methods of data selection and analysis. The data was analysed according to Strauss and Corbin's (1990) grounded theory approach to the analysis. Schatzman's Dimensional Matrix (1991) was also used to assist with the analysis of the data. The fourth chapter describes the results of the study and in particular the components of the substantive theory of "conquering the cancer experience" using the elements of context, processes, conditions and consequences. The fifth chapter provides a

discussion of the results of the research in relation to current literature, and offers recommendations for practice. The fifth chapter also summarises key findings, recommendations and implications for practice, and suggests areas of future research.

CONCLUSION

This chapter provided a broad outline of the context for this study. In summary, adolescence is a challenging journey to adulthood. The diagnosis of cancer in adolescence adds extra challenges to this journey. The coping strategies used by adolescents with cancer impacts on their experience. An understanding of the strategies they use to cope with their experience will help health professionals to support other adolescents through this difficult journey.

CHAPTER 2: LITERATURE REVIEW

INTRODUCTION

This chapter will explore research which has previously been conducted into adolescents with cancer. Most previous studies have concentrated on a single issue for adolescents with cancer. Many aspects of the experience for adolescents with cancer have been explored, however overall there has been limited research into adolescents with cancer. The aim of this study was to take a broader perspective in identifying how adolescents with cancer cope with their situation using grounded theory methods.

This literature review aimed to confirm the need for the study as Strauss and Corbin (1998) write “that there is no need to review all of the literature in the field beforehand” (p. 49). To do so may lead the researcher to be overly focused on a specific topic and not able to realise the full potential of the data. The literature review conducted for this study was therefore used to identify a need for research. Further literature has been used in the discussion chapter, and the topics which were important for the adolescents in this study were discussed in relation to current literature.

Through a thorough literature search of the databases of CINAHL, Medline, PsycINFO and ERIC, it was identified that there had previously been only limited research into adolescents with cancer. Adolescents with cancer often have experiences which are similar to adolescents with chronic illness, including hospitalisation, separation from peers, sexuality issues and the potential for school and career disruptions (Lubkin & Larsen, 2002). Therefore, research into adolescents with chronic illnesses has also been incorporated into this review. In particular there had been very few qualitative studies investigating the coping strategies employed by adolescents with cancer. There is limited research into adolescents with cancer in Australia, with no research being performed in Queensland.

In Chapter One, the unique issues of adolescents with cancer were discussed to establish a background of this experience. To evaluate the current research into adolescents with cancer, some of these topics will be revisited including informational needs, relationship with their health team, disruption to peer relationships, sexuality, and future goals and school disruption.

INFORMATIONAL NEEDS

This section will explore the current research into informational needs of adolescents with cancer and chronic illness to determine gaps in knowledge of this important issue.

Hooker (1997) undertook a pilot study in the UK to develop a research tool to identify the informational needs of adolescents with cancer. Hooker also aimed to identify medical professionals' perceptions of the informational needs of adolescents and compared the perspectives of both groups. This pilot study used a convenience sample of seven adolescents with cancer and ten medical professionals from a specialist hospital. To identify which information was most important, a card sort tool utilising Q methodology was developed (Hooker). Q methodology uses a Q-sort procedure, which requires the participants to sort a deck of cards to specific criteria (Polit & Hungler, 1999).

Hooker (1997) identified the informational needs from literature and from experts in the field, adolescents with cancer, their parents, and medical professionals. These needs were printed on 13 cards. The raw data from the card sort was the perceived order of importance. The data from the adolescents and medical professionals were collated separately for comparison.

The comparison between the two groups in Hooker's (1997) study identified differences between the groups. The top three informational needs were, "is the treatment working?", "cure", and "my illness". These needs were the same for both of

these groups but were in a different rank order. This suggests that medical professionals' perception of adolescents' needs differs from their actual needs. This difference highlights the importance of gaining an understanding of the adolescents' coping needs from the adolescents themselves.

Hooker (1997) suggested that the informational needs of adolescents with cancer are similar to those of adult cancer patients. This pilot study found that adolescents were able to identify their needs and prioritise them. The literature review could find no subsequent published material available on the use of the card sort tool.

Dunsmore and Quine (1995) explored the informational, support and decision making needs of 51 adolescents with cancer in Sydney, Australia. They developed a 42 question self-administered questionnaire that consisted of open and closed ended questions. The questions were designed to gain information about demographic data, disease characteristics, coping and support mechanisms, self-perceptions and the adolescents' informational and psychosocial needs. They utilised a literature search and focus groups to help design the questionnaire.

The questionnaire for Dunsmore and Quine's (1995) study was administered to all of the adolescents attending a 1992 CanTEEN camp. Table 1.1 (on page 11) includes information regarding CanTEEN. Fifty-five adolescents were given the questionnaire. Fifty-three adolescents returned a completed questionnaire, two of these adolescents were not eligible for the study as they had a life-threatening blood disorder and not cancer. The 51 questionnaires were content analysed and coding categories were developed. Three main sources of information were identified by the adolescents, firstly private discussions with medical professionals, secondly discussions with parents, and thirdly discussions during ward rounds. Nineteen of the respondents felt that they were fully informed, 24 felt they were partially informed,

and the remaining eight felt they were uninformed. More than half of the adolescents preferred to have their parents present when discussing their care with physicians.

Dunsmore and Quine (1995) also gathered information from the adolescents on communication with health care providers. They identified four main factors which influenced education, listening and allowing feedback on questions, expressing concern for the patient, a sense of humour, and confidence in the medical professional's ability and honesty were all important in the professional and adolescent relationship.

Dunsmore and Quine's (1995) study indicates that adolescents with cancer are able to clearly articulate their educational needs. However, the participants in this study were in a support group which may influence their responses compared with those who are not involved in a support group.

In summary, these two studies show that adolescents with cancer have informational needs and they are able to identify what impacts on meeting these needs. There were a few limitations to these studies. Hooker (1997) study used a quantitative approach which, although valid, may not have allowed the participants the opportunity to fully express themselves. Dunsmore and Quine's (1995) study was conducted at a CanTEEN camp which may have impacted on the responses the adolescents gave. Currently in the data there is no information available about how informational needs impact on the adolescents coping with their situation.

RELATIONSHIP WITH THEIR HEALTH TEAM

Adolescents with cancer spend a lot of time in hospital and rely on their treatment team to provide care, support and to educate them through this period. No studies on this aspect of the experience of adolescents with cancer were found during the literature review however a qualitative study of adolescents with a chronic illness is reviewed here.

Woodgate's (1998) study involved adolescents with chronic illness and this was the only paper on adolescents' relationships with their healthcare team that was found within the literature search. Using a qualitative approach allowed the adolescents to explain their story to a fuller extent and did not restrict them in their topics of exploration. Woodgate explored the perceptions of adolescents with a chronic illness regarding how health professionals care for them. Twenty-three adolescents from Canada with various chronic illnesses were involved in the study. The adolescents were interviewed with open-ended questions to gain a thorough insight into their experiences with health professionals. The interviews were transcribed and analysed using grounded theory techniques.

There were eight themes that were identified from the transcripts in Woodgate (1998) study. 'Treat me like a person' explained how the adolescents need to be acknowledged as a person not just a disease. They wanted the medical professionals to get to know them. 'Try to understand,' explained how the adolescents wanted the medical professionals to understand what it was like to be an adolescent with chronic illness. 'Don't treat me differently' showed how the adolescents wanted it to be acknowledged that they have a chronic illness, but they also want to be treated similar to their peers. 'Give me some encouragement' explained how they wanted to be encouraged in the management of their disease. 'Don't force me' explained how the adolescents found no benefit in being pressured into doing something they did not want to. 'Give me options' explained how choices made the adolescent feel that it was easier to manage. 'Have a sense of humour' explained how the adolescents preferred health professionals who were cheerful rather than those health professionals who acted in a professional way. 'Know what you are doing' explained how the adolescents wanted staff to be competent when they were caring for them. This study was able to explore how adolescents perceive to be the best way to care for them.

Adolescents with chronic illness are able to explore and describe their perceptions of health professionals. Adolescents with cancer have many of the same needs and issues as adolescents with chronic illness. Therefore, Woodgate's study can be used to help provide insight into what the experience would be like for adolescents with cancer.

This study on chronic illness indicates that this topic should be investigated further. Relationships with healthcare providers may form an important component of the health needs of an adolescent with cancer. The treatment team play an important role in the adolescents experience with cancer and they could have an impact on the adolescents coping with their experience.

DISRUPTION IN PEER RELATIONSHIPS

For adolescents, relationships with peers are important (Santrock, 2001). Adolescents who have cancer may find that their relationships are disrupted due to missing school. School is very important for most adolescents, as it is where most of their socialisation occurs. Three studies that investigated peer relationships are reviewed here. These studies were conducted with adolescents with cancer and confirm that relationships do play an important part in the adolescent coping with their experience.

Glasson (1995) conducted a pilot study of five adolescents with cancer and their return to school after a period of time away for treatment. The study was conducted in the Channel Islands. Glasson used a descriptive and exploratory approach utilising semi-structured interviews, and grounded theory for the analysis. She interviewed adolescents from a single hospital in the outpatients' department, and from the initial interviews discovered that she needed to find out more information about the hospital school. A second interview was therefore conducted to identify the issues in this area.

Glasson (1995) identified three main themes from the data, disruption, adaptation, and normality. The main disruptions were being behind in school work, peer reactions, hair loss, and overprotective teachers. The adolescents were able to adapt in order to deal with the disruptions and eventually achieve normality.

Rudin et al. (1988) measured the psychosocial concerns of adolescents with cancer. They utilised a semi-structured interview and a Thematic Apperception Test (TAT) to gather information for the study. The TAT is a projective technique similar to Rorschach's inkblot test. The TAT usually consists of 20 cards that have pictures printed on them. The participants are required to invent a story about the picture on the card, about what the person is feeling and how the story will end. These responses are then scored according to the interest of the investigator (Polit & Hungler, 1999). The TAT in this study was analysed by a consulting clinical psychologist, and the interviews were coded for themes by the investigator.

The TAT utilised in Rudin et al. (1988) study consisted of seven cards and there were also seven interview questions. The seven participants were from a haematology/oncology clinic in a hospital in the USA. The themes identified by analysis were divided into three main categories: physical, psychological and social concerns. In the physical category, participants were concerned with medical treatments and the effects of treatment such as bruising, decrease in appetite, decrease in energy, and hair loss. The psychological category included concerns about diagnosis, death and development. The social category included information about family, peers and medical staff. This study utilised two different methods to gain an understanding of the concerns of adolescents with cancer. The interview identified the participants' concerns with knowledge and comprehension while the TAT process identified emotional concerns. Methodology using the TAT appears to be unique when investigating the needs of adolescents with cancer.

Hodges, Graham-Pole, and Fong (1984) investigated the peers of adolescents with cancer and their attitudes, knowledge and behaviours of the adolescents who have cancer. The literature review found no other studies that looked at this phenomenon. A fifty-item questionnaire was developed. Answers were true, false, and unsure. The sample included 65 peers of adolescents who have cancer. The peers stated that they had a positive relationship with their classmate with cancer, which the researchers found was in contrast to studies into the adolescents' perceptions of peers. They also identified that this was the first study to look at the peer's attitudes rather than how the adolescent with cancer felt. This may explain the difference in the results. This study was limited, and it could indicate that further research comparing the difference between the perceptions of adolescents with cancer and their peers, in relation to attitudes towards cancer, would be useful.

In summary, these studies identified knowledge about peer relationships and their importance to adolescents with cancer. There seems to be limited information into adolescents with cancer missing school and how this impacts on their peer relationships. Disruption in peer relationships may impact on the adolescent's ability to cope with their experience.

SEXUALITY

An adolescent's developing sexuality is one of the components of their development to adulthood. There is a lack of current research about sexuality and adolescents with cancer. Chambas' (1991) study of sexual concerns in adolescents is the most recent study in this area. Berman et al.'s (1999) more recent study investigated sexuality in the physically disabled adolescent.

Chambas' (1991) study identified the sexual concerns of adolescents with cancer compared to adolescents without cancer in the USA, utilising a 41 item self-report questionnaire. Chambas developed the questionnaire in collaboration with an

oncology clinical nurse specialist. The questionnaire consisted of demographic data, a Lickert scale, statements of concern and yes/no responses from the adolescents.

Nineteen adolescents with cancer were recruited through two hospitals while 22 adolescents without cancer were recruited through general health maintenance clinics at the hospitals. They were given the questionnaire to complete and return via a reply paid envelope. The results indicated little difference between the two groups. Reproductive issues were the only significant difference between the two groups. This study shows that adolescents with cancer have many of the same struggles with sexuality as other adolescents.

A more recent study by Berman et al. (1999) investigated the sexuality of adolescents with a physical disability. They utilised the Sexual Knowledge Interview Schedules, which consisted of a 42 open-ended question interview. These questions covered the areas of feelings, body part identification, body part function, general sexual knowledge and potential for abuse. The interviews were coded into close-ended codes. The researchers also developed a relationship questionnaire to identify the adolescents' understanding of sexual behaviour, expectations for sexual relationships, perceptions of their ability to participate in a sexual relationship, and the impact of their disability on their sexuality.

The sample in Berman et al.'s (1999) study included 29 adolescents from several cities in Canada. The results of the study indicated that the participants desired to develop sexual relationships, although they had limited knowledge about them and how their disability could affect a sexual relationship. Most of the adolescents felt that they would like information given to them individually, rather than in a group situation. This study utilised interviews to gain an in-depth understanding of the sexuality of the adolescent with physical disabilities. However adolescents with

cancer may have different needs regarding sexuality. They often have problems with self-esteem and body image because of the treatments they must undergo.

Identifying the needs of adolescents with cancer in relation to their sexual relationships will help to improve the services available to them. There is a lack of research into adolescents with cancer and their sexuality which may be important because of the impacts of body image and in particular, fertility. Sexuality is an important component of the adolescent's development to adulthood and there is limited research in this area. Adolescents with cancer are separated from their peers at a time when they are developing a sexual identity and this may have an impact on their ability to cope with their situation.

SCHOOL DISRUPTION AND FUTURE GOALS

There are a number of studies into adolescents with cancer and school disruption and future goals. School disruption due cancer treatment can have an impact on the adolescents future goals. There are three studies reviewed here which although not focused specifically on school disruption and future goals did have findings about the topic. Identifying what the adolescents are doing with their education when they cannot attend school will give an insight into how their schooling, and therefore their future goals, are being managed.

Stern, Norman and Zevon (1993) studied self-image and perceived social support as indexes of adjustment in adolescents with cancer. They compared a group of 48 adolescents with cancer and 40 adolescents without cancer. The adolescents with cancer were recruited from three city hospitals in the state of New York in the USA and the adolescents without cancer were accessed from one of the three hospitals. They utilised three measures in their study. Firstly the Offer Self Image questionnaire, which assesses the adolescent's self image. Each adolescent answers 130 items on a Lickert scale. Secondly, the Social Provision Scale which measures perceived social

support, utilising a 24-item Lickert scale questionnaire. Thirdly, the Career Development Assessment Inventory which utilises semi-structured interviews to assess adolescent developments.

Stern et al. (1993) identified that the age an adolescent was treated for cancer affected their future goals and career aspirations. Younger adolescents who had cancer were delayed in their career development, while adolescents who had cancer at an older age, had higher levels of career maturity and progression than did adolescents without cancer. They also found that only ten percent of the adolescents had experienced problems with employment due to the diagnosis of cancer.

Rudin et al. (1988), in their study into psychosocial concerns discussed on page 21, found that of the 49 responses to developmental concerns, ten were concerned about school, five about career, three about work, and two about intimacy. This study is now seventeen years old and the information may not be relevant for adolescents who have cancer in 2001, due to changes in treatment and school structure.

Glasson's (1995) study about re-entry to school for adolescents with cancer, reviewed earlier in the section about disruption in peer relationships (page 19), identified that treatment for cancer had caused disruption in their school lives which resulted in them being behind in their school work. This study did not investigate the adolescent's future goals and whether they were impacted by their experience. Glasson also found that adolescents attending the hospital school did not perceive this to be useful other than as a distraction technique.

In summary, there does not appear to be specific studies on the future goals and school disruption of adolescents with cancer and therefore the impact of the disease on their development. Most of the articles related to school disruption and future goals for adolescents are more than eight years old. The impact of school disruption and future goals on the adolescents' ability to cope has not been investigated.

SUMMARY

This literature review has examined existing research on adolescents with cancer, through the issues identified in the background section in Chapter One, that caused particular problems for the adolescents. These issues included informational needs, relationship with their treatment team, disruption in peer relationships, sexuality, and future goals and schools disruption. Each of these issues can impact on the adolescent's ability to cope with their experience. Although there has been research into adolescents with cancer, it has been limited and generally quantitative in design. This research project aims to explore how adolescents with cancer cope with their experience, rather than concentrating on one specific aspect of the experience.

Throughout the literature review there has been a wide range of methodologies used, including both qualitative and quantitative approaches. Importantly most of the research has been conducted overseas, and the research performed in Australia has not involved Queensland adolescents, indicating that there is a gap in the available research. This research project aims to help fill the gaps in research about coping and the adolescent with cancer utilising a grounded theory approach as described in Chapter Three.

CHAPTER 3: METHODOLOGY

INTRODUCTION

This chapter will present the research methodology and design for this study. An overview of the theoretical foundations of constructionism and symbolic interactionism is included to provide an understanding of the research epistemology. In addition, the methods of data collection and analysis are described and justified in relation to grounded theory, and the ethical considerations required for this study will also be outlined.

Data for this study were gathered during a previous Royal Children's Hospital (RCH) research project, which involved interviews of adolescents with cancer for a needs analysis. Seven of the interviews conducted in the RCH project were re-analysed for this study using grounded theory methods. The data analysis methods used for this study included theoretical sampling, open, axial, and selective coding, memo writing, and identifying a central category through the use of Schatzman's (1991) Dimensional Matrix.

The original aim of this study was to determine how adolescents with cancer manage their situation. However, after the initial analysis of the interviews the central issue that emerged was how adolescents coped with their situation. Therefore the objectives of the study became, what resources do adolescents utilise to cope with their experience and what coping strategies do adolescents use to cope with their experience. The following chapter will discuss the methods used, supported by examples of their use from the analysis.

From the epistemological standpoints of constructionism and symbolic interactionism, a grounded theory approach was used to explore the participants' experiences of coping with cancer during adolescence. A grounded theory approach is best used on a small scale to explore situations where there has been little research and

where processes, relationships, meaning and adaptation are the focus (Grbich, 1999).

The literature presented in Chapter Two demonstrated the lack of research into adolescents with cancer, particularly in Australia.

METHODOLOGY

The epistemological stance of constructionism implies that the researcher believes that meaning is constructed and not simply discovered (Crotty, 1998). Crotty writes that meaning is a concept initiated and developed by humans as a way of interpreting the world around them. The term social constructionism refers to the fact that one's culture designates certain meaning to one's reality. Therefore an individual's culture dictates how they see and construct meaning in their lives (Crotty). Grounded theory methods were used to gain an understanding of how adolescents with cancer construct meaning in their lives.

Symbolic interactionism is a theoretical perspective developed with the epistemological position of constructionism (Crotty, 1998). It describes the experience of the development of one's self and one's relationship within society. Symbolic interactionism also focuses on the development of the person's identity and their philosophical position in society. From the epistemological standpoint of constructionism and the theoretical perspective of symbolic interactionism, grounded theory focuses on identifying what is happening in the everyday lives of the participants (Grbich, 1999).

Symbolic interactionism explores how society as a whole relates to a phenomenon (Berger & Luckman, 1979). This theoretical perspective leads to an overall approach to research. Therefore, this research used a symbolic interactionist approach rather than concentrating on specific incidences that occurred to the participants, and consequently an understanding of what the whole experience was like has been identified for this particular population of adolescents with cancer.

From a constructionist view, research helps in the construction of knowledge about a particular subject (Crotty, 1998). These philosophical and theoretical approaches are often applied in qualitative research designs because they can be directly related to problems within society (Berger & Luckman, 1979). Therefore qualitative research does not need to be generalised to be useful as a data source, although the application of the research methods should be rigorous.

QUALITATIVE RESEARCH

Qualitative research has developed as scientists have become more aware of the value of the exploration of experience. Qualitative research involves exploring the participants' life from their perspective (Grbich, 1999). A qualitative inquiry methodology was used in this study, because it allowed the researcher to explore the coping mechanisms of adolescents with cancer from their perspective.

Qualitative research has been described as the search for an understanding of the experience for the participants (Grbich, 1999). To achieve this in qualitative research, the conceptual and methodological techniques are used to gain an understanding of the participants' life from their perspective, while taking into account the dynamic nature of the participants' society. The researcher gains information through varied data collection methods. The data is analysed into phenomena which are important to the participants and the findings are described in the words used by the participants (Minichiello, Aroni, Timewell & Alexander, 1995).

The literature review in Chapter Two showed that most of the research on adolescents with cancer has been qualitative and there has been limited research into the experience of adolescents with cancer. Therefore, research into this area will help with the construction of knowledge relating to adolescents with cancer coping with their experience.

Qualitative research does not aim to be representative of everyone within a given population in society, although it should represent what is happening to the group being studied. The theory may be applicable to others going through the same situation, but this should not be assumed (Grbich, 1999). For example, adolescents with cancer in Queensland may have different experiences to those in the United Kingdom or Asia due to social and geographical issues.

This study fulfils the requirements of qualitative research as it will describe the experience of the participants in their words and provide a new perspective into the participants' lives. There are various approaches or methodologies that can be used to achieve an understanding of the participant's life (Grbich, 1999). The grounded theory approach was used in this study with foundations in symbolic interactionism and constructionism.

GROUNDING THEORY

The grounded theory method of inquiry was developed by Glaser and Strauss in 1967, in response to their inability to gain symbolic meaning with their research into the meaning of dying for individuals and their significant others. They adjusted the available methodologies to suit their requirements (Stern, 1994). In grounded theory, it is important to begin with a broad topic and allow the theoretically relevant data to become evident. This means that the generation of a theory occurs without an initial hypothesis (Wimpenny & Gass, 2000). In the development of a grounded theory, techniques of constant comparison and theoretical sampling occur simultaneously. The constant comparative method involves the researcher comparing each incident within the data with the developing theory to ensure that they relate to the same topic. Theoretical sampling involves sampling data to explore and improve the emerging theory (Strauss & Corbin, 1998). The data is coded into preliminary categories, which are then constantly compared against each other, as new data are collected and coded.

The theory emerges from these codes which in turn guides further data collection or selection until there is a point of theoretical saturation (Locke, 1996).

The development of a theory can result in a substantive or formal theory. A theory provides a framework for explaining what is happening to the participants. A substantive theory explains how specific participants manage their problems, as opposed to a formal theory which provides a more general framework to explain what is happening to a number of social groups (Strauss & Corbin, 1998). A formal theory's framework often incorporates a number of substantive theories (Glaser, 1978). A grounded theory should be able to predict and explain behaviour, theoretically advance research, have practical applications, provide insight into the behaviour, and guide further research in the area (Grbich, 1999). This study aimed to develop a substantive theory to explain and provide insight into the coping behaviours of adolescents with cancer. A theory helps to explain why the facts exist for the participants and are generally assumptions of what is happening (Chafetz, 1978).

In summary, a grounded theory provides a conceptual analysis of what is happening and allows the identification of problems so that solutions can be put forward to ease these problems. A grounded theory is identified from the data and reflects what is happening to the people being studied. The theory is created from the data to facilitate and express what the participants are describing as their experience. The grounded theory techniques described by Strauss and Corbin (1998) are more structured and provided a clearer explanation for the researcher and have been used for this study. The following section describes how these techniques were applied for this study.

Grounded theory techniques

This study used various grounded theory techniques as described by Strauss and Corbin (1998). The two main techniques are constant comparison and theoretical

sampling. These techniques are the backbone of the grounded theory method and adherence to them assists the researcher to rigorously develop a theory.

Constant comparison

Constant comparison is often used in social research and is considered a general method of analysis. Using constant comparison to generate a theory allows the method to be used in a wide range of applications such as small or large groups (Glaser & Strauss, 1967). Glaser and Strauss explain that the constant comparative method used in grounded theory is specific to this methodology.

Constantly comparing data throughout the generation of a grounded theory allows identification of variations within the data. Throughout the analysis it is important to compare each incident with each other, and in turn each category with each other. Comparison is made through asking questions of the information to make certain they are similar. Understanding the different properties and dimensions of an experience helps to provide an understanding of what is happening to the participants (Strauss & Corbin, 1998). The use of constant comparison in this research allowed the theory to emerge from the data. Identifying the similar experiences helped to increase understanding of the adolescents' experiences.

Sampling

The process of sampling in grounded theory is known as theoretical sampling. The researcher is sampling data and not participants, although they may use participants to obtain this data. The aim of theoretical sampling is to ensure that the researcher takes full advantage of the available opportunities for comparison between events (Strauss & Corbin, 1998). During theoretical sampling the researcher collects, codes and analyses data simultaneously. This leads the researcher to the next source of data depending on the emerging theory (Coyne, 1997). Throughout the process of coding, the researcher decides what areas need further investigation, depending on the

developing theory, and samples data in these areas (Locke, 1996). The process of theoretical sampling involves open sampling, relational and variational sampling, and discriminate sampling. These forms of sampling occur as the process of analysis develops (Strauss & Corbin). Theoretical sampling occurred throughout the analysis phase of this research. Each interview was selected according to the techniques described by Strauss and Corbin and Minichiello et al. (1995).

Various forms of data may be used in the development of a grounded theory, including interviews, field notes, or any sources of written and pictorial documents (Strauss & Corbin, 1994). The primary data source for this study was a cache of 28 qualitative interviews conducted 12 months prior to this study's analysis. Glaser and Strauss (1967) describe the technique of using previously collected data for analysis as secondary analysis. Secondary sources of data (Glaser & Strauss) for this study included the personal experience of the researcher in working with adolescents with cancer, and other literature in the field. The cache of interviews was collected through a research project conducted at the RCH in 2001, and is described below.

Royal Children's Hospital Research Project

The RCH research project was conducted in 2001 and aimed to identify the needs of adolescents with cancer in Queensland. The researcher was employed to undertake this needs analysis. Ethics approval for the project was gained through the RCH Ethics Committee (see appendix 1). Adolescents were recruited from the RCH, Townsville General Hospital, Camp Quality and The Leukaemia Foundation. Twenty eight adolescents were involved in the RCH research project. These adolescents were contacted via telephone by the researcher to organise a time for the interview. The interviews were conducted either at the RCH, the participant's home or via a telephone interview. Each interview was recorded and transcribed verbatim by the researcher.

The interview questions for the needs analysis were based on the five issues identified through the literature review, these were informational needs and relationship with the treatment team, family relationships and developing independence, sexuality, future goals and school disruption, and peer relationships and social life. Initially broad questions were asked such as “What was hospital like?” The adolescents seemed to find it difficult to respond to such broad questions, and as a result an interview schedule was developed see Appendix 1 and used for each interview.

The ethical considerations for this project included consent, and the protection of a potentially vulnerable population. Prior to being interviewed the adolescents signed a consent form to participate in the research. On this consent form they also consented to the information being used for further research. Participants in this project were aged between ten and 19, and if the adolescent was a minor their parents also signed the consent form. The inclusion criteria were developed to include appropriate participants in the research and protect particularly sensitive patients. Adolescents not in remission or not receiving active treatment were excluded from this project to prevent further burden on them.

Table 3.1 - Inclusion criteria for the RCH project

The adolescent will:

- have received cancer treatment after their 10th birthday and before their 20th birthday.
- be receiving active treatment.
- have received their treatment after January 1996.

The transcribed interviews were then coded for content analysis and 15 themes were identified. From these themes recommendations were made to improve the

experience of hospitalisation for adolescents with cancer. Currently, funding is being sought support the implementation of these recommendations.

Ethical Considerations

Many of the ethical issues that arise when dealing with minors do not apply within this study due to the use of secondary data sources. Ethical considerations that do apply include ethics committee approval, storage of the data and identifiable data. The data were collected via the RCH project and were used with the permission of the participants and the project supervisor. The project was approved by the ACU-HREC (see Appendix 2). Identifiable and demographic data relating to the participants is being kept in a locked cabinet at the RCH and the interview transcripts and tapes were coded so the participants' names were not on the documents. The interviews were coded according their rank in the interview process. There was a corresponding table which allowed the investigator to identify which document belonged to which adolescent. This table is also kept in the locked cabinet at the RCH. Due to the coding system used for the RCH project, the secondary data sources had no identifiable data on them. The demographic data were accessed to complete Table 3.3 and was returned to the locked cabinet at the RCH. The names used within this and following chapters are pseudonyms.

Theoretical Sampling

Data for this current research into the coping strategies of adolescents with cancer were selected from the RCH project interviews. The interviews were selected according to the principles in grounded theory of theoretical sampling (Strauss & Corbin, 1998). Seven of the transcribed interviews were selected for secondary analysis.

Open sampling involves gathering data from sources that will provide the researcher with the widest opportunities for revealing what the experience is like for

the participants. The choice of these sources may be random or methodical by following a list (Strauss & Corbin, 1998). The researcher should be open to all ideas and incidences that occur in the data. Strauss and Corbin state that it is important not to follow a list too tightly in order to allow the sampling to flow freely as the theory develops. The sample chosen is often based on the convenience of the participants, the researcher and the environment (Strauss & Corbin). Open sampling occurred in this research through a random selection of two interviews. The remaining five interviews were selected using the theoretical sampling guide to maximise variation in the data.

During open sampling Strauss and Corbin (1990) suggest using a list to help in the process of sampling. This guide can be developed from evidence in the literature (Minichiello, et al., 1995) and may also include the researcher's personal experience as valid data as described by Glaser and Strauss (1967). Table 3.2 displays the theoretical sampling guide for this research.

Table 3.2 - Theoretical sampling guide.

- | |
|--|
| <ul style="list-style-type: none"> • Distance from treatment centre <ul style="list-style-type: none"> ▪ Adolescents with cancer who live greater than 100 kilometres from Brisbane. ▪ Adolescents with cancer who live in metropolitan Brisbane • Gender <ul style="list-style-type: none"> ▪ Female adolescents with cancer. ▪ Male adolescents with cancer. • Developmental Stage <ul style="list-style-type: none"> ▪ Adolescents with cancer in early adolescence. ▪ Adolescents with cancer in middle adolescence. ▪ Adolescents with cancer in late adolescence. • Siblings <ul style="list-style-type: none"> ▪ Adolescents with cancer who have siblings. ▪ Adolescents with cancer who do not have siblings. • Treatment Stage <ul style="list-style-type: none"> ▪ Adolescents with cancer who are six weeks into treatment ▪ Adolescents with cancer who are six months into treatment ▪ Adolescents with cancer who have finished treatment |
|--|

Some of the participants may meet more than one of the criteria on the theoretical sampling guide. The development of the theoretical sampling guide aimed to cover most of the variables within the population, as identified through the literature

review and the researcher's observations in clinical practice. Strauss (1987) described the importance of selecting data through searching for contrasts. The theoretical sampling guide assists researchers with exploring the dimensions of the experience for the participants.

The theoretical sampling guide for this research was based on the following rationales. Distance from treatment centre was identified as a topic that had limited coverage in previous research into adolescents with cancer. There has been significant research in Queensland which has focused on the adult oncology population. The findings of this study may identify a difference between adults and adolescents. It was anticipated that the adolescent's gender may provide different data and so was included as part of the sampling guide. It was also important to include adolescents in all stages of development, early, middle and late adolescence as discussed in Chapter One. Siblings may also influence the adolescent's experience, therefore adolescents with and without siblings were included in the research to help identify how important they were for the adolescent with cancer. The treatment stage was also identified as having the potential to influence the experience of the adolescent with cancer.

During relational and variational sampling the researcher is looking for dimensions or variations within the data. The researcher samples incidents that occur to help demonstrate the variations within the data. Through discriminate sampling the researcher selects data that ensures comparative analysis. The aim of dimensional sampling is to use the data to develop a theory (Strauss & Corbin, 1998). Through analysing the data, comparison between the variations occurs. The interviews were selected in this process according to the theoretical sampling guide to ensure that variation within the data was as wide as possible. Table 3.3 (page 38) shows the demographic information for the adolescents whose interviews were included in this research.

Table 3.3 - Participants

Pseudonym	Age	Age at diagnosis	Diagnosis	Treatment	Siblings	Parents	Distance of home from treatment centre	Hospital treated
Steve	19	18	ALL Philadelphia chromosome +ve	BMT still on immunosuppressants. Chemotherapy and radiation prior to BMT	2 B 1 S	Mother (Father died when young)	30 min drive	A
Frank	19	19	Germ Cell Tumour	Recently finished chemotherapy.	1 S	2 Parents	1000 km	A
Chris	16	15	ALL	Just finished chemotherapy.	4 S 1 B	2 Parents	>1000 km	A
Sally	14	12	Mature B-Cell Lymphoma	Finished treatment 1 year ago. Treated with chemotherapy and radiation.	No siblings	Lives with mother *	45 min drive	P
Joshua	13	12	Ewings Sarcoma	6 months since diagnosis. Treated with chemotherapy.	No sibling	Lives with mother *	<30 min drive	P
Eliza	12	12	Ewings Sarcoma	Just finished treatment with surgery, chemotherapy and radiation	2 S 1 B	Lives with parents	30 min drive	A
Mark	15	15	T-Cell Lymphoma	6 weeks since diagnosis treated with chemotherapy	1 S	Lives with mother *	15 min drive	P

Key

A = Adult Hospital

P = Paediatric Hospital

* = Parents divorced prior to diagnosis

S = Sister

B = Brother

For further abbreviations see page v.

A grounded theory approach to analysis

Qualitative analysis involves the organisation and exploration of data to uncover relationships between each piece of data (Polit & Hungler, 1999). To develop a grounded theory certain steps are required, including open, axial and selective coding, and although these steps are identified as ways of coding, they involve in-depth conceptualising of the data. The analytic tools of microscopic analysis and memo writing assist in the development of a grounded theory. The process of developing a grounded theory is a fluid one, and often moves in a cyclical pattern between the different stages of analysis as the theory takes shape. This is achieved through moving between each type of coding and analysis technique, depending on the

needs of the analysis, in a cyclical process to develop the theory (Strauss & Corbin, 1998).

Open Coding

Open coding involves breaking the data up into discrete individual events. An event is anything which is important to the participants. The data is broken up into discrete events through the process of microscopic analysis. These events are assigned names and are known as codes. Once the data are broken up into codes, the researcher uses the technique of constant comparison to combine the codes into concepts and then into categories (Strauss & Corbin, 1998). This process will be further discussed below in relation to this project.

Microscopic analysis

Microscopic analysis is a line-by-line analysis of the data to help the researcher identify codes and categories. Microscopic analysis is a process involved in both open coding and axial coding and involves an exploration of each word, phrase, and sentence, to gain an understanding of what the participants are saying (Strauss & Corbin, 1998).

Strauss and Corbin (1998) believe that it is impossible to be totally objective when working with qualitative data. Therefore using the experience and knowledge of the researcher sensitises them to the properties and dimensions of the data. The researcher's experience and prior knowledge can be used to help the researcher be sensitive to issues for the participants, but should not be used as data or to strictly guide the analysis (Strauss & Corbin). Within this study the researcher's prior knowledge was used in developing the theoretical sampling guide and helped in the selection of the interviews to gain the best data. Through using a line-by-line approach to analysis, the researcher is open to the complete range of the data, which helps to

prevent the researcher from bias in developing the theory due to preconceived ideas about the data or theory (Strauss & Corbin).

The events identified by the microscopic analysis are assigned an identifier and these names are known as codes. The identifier of each code may be *'in vivo'* (Grbich, 1999, p. 176), a term that the participants used, or a sociological term (Grbich).

Exploring each word, phrase and sentence of the data allows the researcher to understand and interpret what the experience is like for the participants. Breaking the data down into codes allows for comparison between the data, and the constant comparative method. Microscopic analysis involves the use of questions to identify the 'who, when, what, how and why' (Strauss & Corbin, 1998, p.66) of the theory. The data and the overall understanding of the experience is what is important in a grounded theory, not specific or separate events that occur in the experience (Strauss & Corbin).

Through exploring each word, phrase and sentence in the following section of data, the researcher identified five events. Exploring the data so comprehensively helped to identify what the experience was like for the participants. This process of microscopic analysis was useful throughout the coding process, but especially in the open coding phase. The bolded phrases relate to a code which is found in the parenthesis.

Sally – *Um pretty much everything else... **The food I didn't really like that** (didn't like the food) *I don't know if that was chemo or just me. But um.... I also **didn't like the side effect of chemo** (side effects of treatment) and the needles and all the other type of operating things they had to do. **Putting me to sleep all the time waking up feeling muggy** (feeling yuck). Um... pretty much **just staying in there for the rest of the year** (staying in hospital for so long).**

The microscopic breaking up of the data may lead to numerous codes which would be impossible to continue to analyse and gain meaning. The next step is to cluster the codes into similar groups known as concepts. The concept should contain codes that explain a similar event. The use of the constant comparative method is

important when condensing codes into concepts (Strauss & Corbin, 1998). An example of this follows (Table 3.4) when Joshua and Sally spoke about not knowing what they wanted to do for a career.

Table 3.4 – Developing Concepts

<i>Code</i>	<i>Concept</i>
<i>Never thought of a career</i> Joshua – Never thought of it (career options)	<i>Not knowing what to do for a career</i>
<i>I don't know what to do</i> Sally – Um I've had a lot of thought about this (career options) and I seriously don't know.	

These two codes have been identified as being about the same topic and combined into a concept.

The concepts can be further condensed into a category. A category is a more abstract approach to data organisation. A category can explain a variety of events about a similar concept. Each category should be given a definition to allow the researcher and others reading the research to understand what the category is about. During open coding the researcher initially identified 97 open codes from the initial two interviews of Sally and Joshua. There were 37 concepts developed from these codes which were then collapsed into seven categories: effects on schooling, life after treatment, job options, hospital environment, sequelae of treatment, wanting to be normal, and staff characteristics.

Table 3.5 (page 42) shows an example of the steps involved in developing the category of job options through the constant comparative process. The initial open coding revealed four codes, these were 'never thought of it', 'I don't know what to do', 'many options for a career', and 'not wanting to miss out on job opportunities'. Through comparing the data within these four open codes it was identified that these codes were all about potential career options, and therefore were grouped into the category of job options. The definition of Job Options was the effect of treatment on

career prospects. Throughout the analysis phase the researcher revisited open coding and subsequently re-categorised certain codes following the free flowing process of analysis, always utilising the constant comparative techniques, and grounding the developing theory in the data.

Table 3.5 – Developing Categories.

<i>Open Codes</i>	<i>Concept</i>	<i>Category</i>
<i>Never thought of it</i> Joshua – Never thought of it	<i>Not knowing what to do for a career</i>	<i>Developing new career pathways.</i>
<i>I don't know what to do</i> Sally –Um I've had a lot of thought about this (career options) and I seriously don't know.		
<i>Many options for a career.</i> Sally – At one stage I wanted to be a doctor so I could help out people who were like me. Or a nurse. But then I thought no cause then I'd go home and I don't think I'd feel that well I'd be like I don't want them to go through all this and I'd feel very emotional about it. But then again that might be a good thing it might make me more motivated so I think that's a thinking thing that's definitely still in thought. And then I was thinking maybe something totally different maybe going into a business where I just have to go from nine to five and do what ever I want in the afternoon. Some thing more in the business field or hospital.	<i>Job opportunities</i>	
<i>Not wanting to miss out on job opportunities.</i> Sally -Cause you know I didn't want to go into life well I couldn't do this just because I had cancer.		

Once categories are identified it is important to develop them further by expanding the properties and dimensions of the category. A property describes a characteristic within the category, and dimensions look at the variation along a range within the category. To identify the properties and dimensions of a category involves asking “when, where, why, who, how, and with what consequence” (Strauss & Corbin, 1998, p. 125) within each category. The answers to these questions within the data help to identify the properties of the data. The dimensions of a category involve identifying a continuum of situations that occur for the participants. The properties and dimensions of a category are important because they are used when comparing

situations. The researcher compared each of the situations within the data, taking into consideration both the properties and the dimensions of this data. Categories also include subcategories which are categories that help to explain the properties and dimensions of a particular phenomenon (Strauss & Corbin). The properties and dimensions of the category *gaining control* are described in Table 3.6 (page 44).

Axial Coding

During open coding the data were separated into separate codes. Axial coding involves bringing the data together to provide an understanding of a particular phenomenon. There may be many phenomena within the data and axial coding allows the researcher to see these phenomena and how they relate to each other. Strauss (1987) described four tasks that occur in axial coding: identifying what the properties and dimensions of a category are, describing how categories and subcategories relate to each other, discovering what the relationships are between the major categories, and uncovering the conditions, actions/interactions and consequences for the phenomenon. The first three are a continuation from open coding. The fourth according to Strauss and Corbin, involves the use of a paradigm (Strauss & Corbin, 1998). Leonard Schatzman developed a matrix to simplify and structure this process in axial coding (Kools, McCarthy, Durham, & Robrecht, 1996).

A category helps to explain a phenomenon. A phenomenon could be a problem, event, or issue that is important for the participants. Within each category there are data and codes to describe the properties and dimensions of the phenomena. Using the questions of ‘when, where, why, who, how, and with what consequence’ (Strauss & Corbin, 1998, p. 125) helps the researcher identify what the properties and dimensions of each category are. Table 3.6 (on page 44) provides an example of a category and will be used to help identify the dimensions and properties of the category *gaining control*.

Table 3.6 - Combining Sub-Categories into Categories.

Open codes	Concepts	Sub-category	Category
<ul style="list-style-type: none">• Explaining helped• Mum explained it more to me.• Side effects more information when you got them.• Face to face education on treatment and side effects• Appropriate language• Experiencing it is the best way to learn.	Learning	Keeping informed	Gaining control
<ul style="list-style-type: none">• Giving info to you slowly so you can absorb it• Not keeping you informed• Staff explained things well• Explain things clearly• Keeping informed• Spoke to parents	Keeping informed		
<ul style="list-style-type: none">• Missing school• Good days bad days• Repeating the year• Keeping up at school	Normal School	Restructuring school program	
<ul style="list-style-type: none">• Teacher bringing work in.• Teacher not pushing• Able to do heaps of school work.	School in hospital		
<ul style="list-style-type: none">• Hope• Being positive• Looking to the future.	Looking to the future	Looking to the future	

The subcategory of *keeping informed* has many properties, which are displayed in the open codes section of the Table 3.6. Strauss and Corbin (1998) describe a property as the qualities of the category or subcategory. They provide the category with meaning. Within the properties there are dimensions which display the variations within the properties. The dimensions of the properties within the sub category *keeping informed* explain how the adolescents used *keeping informed* to help them gain control of their lives.

The process of axial coding occurs simultaneously with open coding. These processes flow well together to develop the dimension and relationships between categories. This leads to the explanatory power of the theory and will continue to develop throughout the process of developing a grounded theory. The way categories

relate should be described in memos, which enable the researcher to describe how they developed the theory and reached their conclusions (Strauss & Corbin, 1998).

Memo writing

Memo writing is an important part of the analysis process. Memos describe the thought processes that lead the researcher to arrive at a grounded theory. Memos allow the researcher to follow their path of discovery and to recreate the research process. According to Strauss and Corbin (1998) there are three forms of memo that occur in a grounded theory analysis. These are code notes, theoretical notes and operational notes. Code notes are utilised to describe the process of coding, theoretical notes describe the researcher's thoughts on theoretical sampling, and operational notes relate to thoughts on the procedure of developing a grounded theory. The process of writing a memo should not be descriptive, but needs to contain conceptual ideas about what is happening in the data. Memos help the data move from a description to a grounded theory (Strauss & Corbin).

The process of writing memos helps to clear the researcher's thoughts on what was happening. Having written memos about the research and thoughts about what was happening, it was possible to go back the next day and have an understanding of what was going on. The following is an example of a memo written during axial coding, and can be classed as an operational note. Operational notes are notes which relate to the procedure of developing a grounded theory (Strauss & Corbin, 1998). This memo shown in Table 3.7 (page 46) helped to develop the focus of the theory in this study. It was also useful when resuming work on the theory after a break and to work out where the analysis was going. The process of writing memos was used throughout this study to help conceptualise the data and develop a grounded theory.

Table 3.7 – Memoing.

I am wondering if it's (the basic social process) never feeling normal again. It's a life changing event. So do they never feel the same as their peers? You get cancer your life gets turned upside down and you come out the other end different and changed. Ultimately you want to survive this situation and your mortality becomes a focus you change the way you look at things.

Not wanting to be normal.

Wanting to know you're normal

Being different not necessarily a bad or a good thing.

Working with this being different to develop into a stronger person.

Challenges and the way they respond to these make them ultimately psychologically stronger. These challenges change them.

Survival → *Being stronger because they were different they needed to use these strategies.*

Being Stronger/Becoming stronger or appreciating life or is this just an outcome.

Selective Coding

Selective coding involves bringing together and identifying the grounded theory through integration and refining the theory. To achieve this there are a variety of techniques. Integration is an important component of selective coding, and describes the process of bringing the data together analytically to form a theory. Strauss and Corbin (1998) have developed several techniques to help the researcher integrate their work. A grounded theory is the researcher's analysis and conceptualisation of the data they have gathered. The initial step in integration is discovering a central category, which is the main idea within the research (Strauss & Corbin).

Discovering a central category

The central category is the researcher's interpretation of the main theme of the data. It describes in a few words the experience of the participants. All other categories must be related to it, so that it is central. The category must appear often in the data. The researcher must not force the data, and there must be logical relationships between the categories. When identifying the central category it must be conceptual so that other research can be undertaken using the theory in other areas. The process of analysis and integration with the other categories should help to

develop the explanatory influence of the theory. The central category should finally be able to explain the dimensions of the data (Strauss & Corbin, 1998). There were several central categories which may have been appropriate for this study. These included, feeling normal, becoming stronger, survival, escaping, and conquering the experience. Identifying a single central category can be difficult, however there are techniques which may help the researcher in this process. Strauss and Corbin (1998) describe four techniques to identify the central category, writing a story line, conceptualisation, reviewing memos, using diagrams. In identifying the central category for this research, the techniques used were writing a story line and Schatzman's Dimensional Matrix (1991).

When attempting to identify the central category the researcher may write a story line outlining their feelings about what is going on in the participants' lives. Writing about this feeling can help to integrate these thoughts and the data (Strauss & Corbin, 1998). The writing of a story line developed as an understanding of what the experience was like for the adolescent and helped in developing the central category, "*conquering the cancer experience*". The central category helps to describe how the adolescents felt and coped with their experience. Once the researcher has identified exactly what the central story is they should give it an abstract name and then try and relate the categories to it. Relating other categories to the central category may be difficult (Strauss & Corbin). Schatzman (1991) has developed a dimensional matrix to help novice researchers in this process.

Schatzman's Dimensional Matrix

Schatzman developed the process of dimensional analysis with his students over a twenty year period to assist them when developing a grounded theory. Through his experience with qualitative research, he identified that students were having difficulties when developing a grounded theory due to a lack of understanding of the

process of grounded theory. He concluded that this was due to the lack of a structural guide to analysis. He has developed this method to either stand alone or be used as a component in the development of a grounded theory (Kools, McCarthy, Durham, & Robrecht, 1996).

Dimensional analysis assists the researcher to progress from descriptive analysis to explaining how the categories interact within the grounded theory. This process helps to organise the components into the conceptual components of context, conditions, process or consequences. The context sets the scene for the research because it describes the environment and situation for the participants. Conditions have an affect on the process and they can assist, interfere, or influence the participant's actions and/or interactions. Processes describe the actions and interactions that the participants were involved in as a response to conditions, and these actions may be conscious or unconscious. Consequences describe the outcomes that occur as a result of these specific actions or interactions (Kools, et al., 1996).

The process of dimensional analysis is based around developing an explanation for what is happening within the data. The context, conditions, processes and consequences give the researcher a framework to develop this story. Schatzman (1991) has developed an explanatory matrix for the paradigm (see Figure 3.1) so that “‘from’ perspective, ‘in’ context, ‘under’ conditions, specified actions ‘with’ consequences, frame the story in terms of an explanatory logic embedded in the following matrix” (Schatzman, 1991, p. 308).

Figure 3.1 – Matrix for explanatory paradigm

(from) Perspective			
(attributes) Dimensions-Properties			
(in) Context	(under) Condition	Action/Process	(with) Consequences
Designations			
(Schatzman, 1991, p. 308).			

The development of an explanatory matrix involves four steps. Initially the researcher needs to identify a central category. Schatzman uses the term dimension to describe categories. This central dimension should provide the best explanation for what is happening in the research. The next step is to arrange the categories within the matrix as context, conditions, processes or consequences. Thirdly, once the researcher has organised the data, they need to theoretically sample to help refine, check, and fortify the conceptual connections within the developing grounded theory. Once the researcher has reached a point of theoretical saturation, no further data collection or analysis is required. Finally, using the central category as the perspective, the other categories should be integrated into the explanatory matrix. Memos allow the relationships between the categories and the central category to be identified. The matrix then assists the researcher to explain the grounded theory in a way that can be understood by the reader (Kools et al. 1996).

Schatzman's Dimensional Matrix has been used from the perspective of “*Conquering the cancer experience*” to provide an explanation for the relationships between categories in this theory. A diagrammatic representation of this is presented in Table 3.8.

Table 3.8 - “Conquering the cancer experience”: Categories and Subcategories.

Context <i>Feeling different</i> <ul style="list-style-type: none"> * Being treated differently by friends * When at home * Being restricted <i>Losing Control</i> <ul style="list-style-type: none"> * Making decisions * Feeling trapped * Feeling in the dark * Worrying * Feeling exhausted 	Processes <i>Escaping</i> <ul style="list-style-type: none"> * Not thinking about it * Play <i>Gaining control</i> <ul style="list-style-type: none"> * Keeping informed * Restructuring school program. <i>Seeking new friends</i> <ul style="list-style-type: none"> * Socialising in hospital * Attending support groups 	Consequences <i>Appreciating Life</i> <ul style="list-style-type: none"> * Being healthier * Feeling stronger <i>Developing new career pathways</i>
<div style="display: flex; justify-content: space-between;"> <div style="width: 45%;"> Conditions <i>Situational issues</i> <ul style="list-style-type: none"> * Distance from home * Age of others in hospital * Food * Available resources. </div> <div style="width: 45%;"> <i>Social supports</i> <ul style="list-style-type: none"> * Parents/family * Peers * Therapeutic relationships </div> </div>		

The process of refining the theory helps improve the logical flow of the theory and reveals inconsistencies within the theory. Inconsistencies within the theory reveal themselves when the theory does not flow, and may be a feeling that something is ‘not right’ with the theory (Strauss & Corbin, 1998). These inconsistencies may arise from the researcher’s perspective as a health professional. For example the subcategory of distance from home seemed to have holes within it as the data didn’t answer the who, what, where and when. Further analysis of the interviews improved the category of distance from home.

Poorly developed categories may become evident in this refining phase. It is important to develop these poorly developed categories from the raw data, searching for data that may have been missed initially using the techniques of open and axial coding. The matrix developed for this study was rewritten a number of times and the data from the seven interviews were further analysed to ensure the final theory was consistent with the adolescents’ experiences.

Theoretical Saturation

Theoretical saturation occurs when there is no new information arising from the data. Saturation occurs on a category by category basis. As each category becomes saturated, the researcher develops the dimensions and properties of the next category through analysing further data (Strauss & Corbin, 1998). In this study it became obvious as categories developed that there were holes within some categories. Strauss and Corbin describe that this may occur. These holes were eliminated through analysis of further data selected with assistance from the theoretical sampling guide.

CONCLUSION

In summary, the process of analysis in grounded theory aims to develop a theory that explains the basic social processes of the participants. This has been achieved through utilising the techniques of open, axial and selective coding. The

basic social process for this group of adolescents with cancer was coping. This coping is described through the central category of ‘conquering the cancer experience’.

The following chapter will describe the results of the analysis described in this chapter. The results have been divided into sections of context, conditions, processes, and consequences according to Schatzman’s Dimensional Matrix. The results from each of these sections will be discussed and supported by verbatim quotations from the adolescents’ interviews.

CHAPTER 4: RESULTS

INTRODUCTION

This chapter will present the results of the study. The aim of this research project was to identify how adolescents with cancer cope with their situation, and to answer the research questions, ‘what resources do adolescents utilise to cope with their experience?’ and ‘what coping strategies do adolescents use to cope with their experience?’ These objectives were met by using the constant comparative techniques of grounded theory and Schatzman’s (1991) Dimensional Matrix. A substantive grounded theory of “*conquering the cancer experience*” emerged. Table 3.8 (on page 49) displays the key categories for this theory.

This chapter will discuss the central category of “*conquering the cancer experience*” (CCE) using the components of Schatzman’s Dimensional Matrix, context, conditions, processes, and consequences. The context of the CCE was reflected in the categories of ‘*feeling different*’ and ‘*losing control*’. The conditions were reflected in the categories of ‘*hospitalisation*’ and ‘*social supports*’, while the processes were categorised as ‘*escaping*’, ‘*gaining control*’ and ‘*seeking new friends*’. The consequences or outcomes of the processes were ‘*changed forever*’ and ‘*developing a new career*’. These components of the results (as shown in Table 3.8 on page 49) form the basis of this chapter. The results will be described with verbatim quotations of the adolescents’ to clarify the meaning. For further verbatim quotations for each category, see Appendix 4 on page 122.

CONQUERING THE CANCER EXPERIENCE

“*Conquering the cancer experience*” was the central category identified in analysing the interview data. It describes how the adolescents coped with their experience of being diagnosed and treated for cancer, and how it impacted on their lives. Ultimately the adolescents in this study had some positive outcomes from

their experience of cancer. The central category of “*conquering the cancer experience*”, has an influence on how each of the categories is linked.

Context of “conquering the cancer experience”

The context for these adolescents with cancer was that they felt different and were losing control of their lives due to their illness. These experiences were interrelated in that the participants often felt different from their peers because they lost control of their situation. The categories are presented separately because they describe different situations and elements of the experience of having cancer.

Feeling Different

The adolescents in this study felt different from their peers when at school, and at home. They felt different because unlike their peers, their activities were restricted due to their illness, and they were involved in a decision making process regarding their health. The dimensions of ‘*feeling different*’ explains the where, when, why, and how the participants felt different as a result of being diagnosed with cancer. The adolescents wanted to feel normal (as they saw it), or just like their peers. They did not feel normal because they had to deal with the situations described above. They perceived their peers at school to be normal, however due to their experience of cancer, they felt they would never be ‘normal’ again, even after having finished treatment. Their challenge of dealing with the cancer experience made them feel they would be changed forever.

Being treated differently by friends

The adolescents who attended school or socialised with their peers while they were being treated for cancer felt different from their peers due to their experience. Often their peers acted differently around them and were unsure of how to interact with their sick friend. This had a negative effect on the adolescent, because they felt their peers did not like them any more. The adolescent with

cancer often felt different at school because people treated them differently. An example of this is that they were not teased because they had cancer, people offered to carry their books, and people were careful not to bump them. Sally found that her peers just acted differently, which led her to feel different because she was not the same as she had been prior to her diagnosis.

Sally *They tried to make me laugh and that was good.
And I knew that wasn't them you know... it wasn't
exactly how they'd act if I didn't have cancer.*

The adolescents also often felt different when they were at home because it emphasised the lack of normality in other parts of their lives.

When at home

When the adolescents were at home they felt normal, but this also highlighted how different they felt when they were in hospital. When they were at home it emphasised the freedom they had, and this was a positive feeling. Sally did not get home often during her treatment but she really appreciated the opportunity when she did.

Sally *...when you're at home you feel more normal. As far
as normal can get... Um you've got friends around.
You've got an actual bed with your possessions around
you. You can eat and drink and move around however
you want.*

Adolescents dealing with the experience of being treated for cancer often found they had less responsibility at home than they did prior to their diagnosis. Frank found that he did not have to do as much around the home as he had prior to his diagnosis. This was surprising for most of the adolescents, as reflected in the following quote.

Frank *Yeah it's really hard to explain there was
suddenly less of everything like that
(housework).*

Most of these adolescents felt that this was a blessing but also that it emphasised that they were different. Although the adolescents felt they had fewer responsibilities, they also had restrictions placed on their lives due to their diagnosis.

Being Restricted

Restrictions that were placed on the adolescents by themselves, their parents and their healthcare providers and interfered with the adolescents' opportunities to be "normal". This group of adolescents felt different because they could not do activities they felt were normal for adolescents to participate in. These restrictions included situations such as going to school, going to movies, and helping out around the house. They felt that these restrictions were placed on them because they were sick or perceived to be sick. This was reinforced by people telling them they could not do things because they were sick. Often the adolescent had scars from their treatment. This also placed restrictions on them because they did not want to do activities such as go to the beach in case people saw their scar and stared at them. The adolescents also realised that there could be negative consequences to their actions so they placed the restrictions on themselves. Chris avoided usual activities because he was scared that even a minor injury was a risk due to his low immunity.

Chris	<i>...one of the bad things is not being able to do something cause you're so scared and stuff.</i>
Interviewer	<i>Scared of what?</i>
Chris	<i>like if you cut yourself and stuff knowing the consequences and that.</i>

The treatment also led to restrictions on the adolescents' lifestyle. If they were not feeling well, they could not participate in usual activities. This led them to feel different from their peers. Mark found that he did not have the energy to do his usual activities. This was a common experience for most of these adolescents.

Mark *...before I'd be able... and be normal I'd be walking around I'd probably be down at the basketball court or over at a friends house or something and wouldn't get home till six o'clock. And now it like I'm home all the time and I can't go to a friends house. I don't have the energy to go to the basketball court like throw a basketball.*

Although the adolescents placed some restrictions on themselves, they also had restrictions placed upon them by their parents, friends and hospital staff. These restrictions included their peers feeling that they could not do something or deal with something due to their illness. Sally found that her peers felt she should not be teased because she had cancer. Sometimes she felt she should be teased because she wanted to be treated normally, and other times when she was feeling sensitive she did not want to be teased.

Sally *But other than that a lot of people were like oh she can't do that she'd had cancer or don't tease her just because she's had cancer....*

Having restrictions placed on them meant the adolescents felt different because they were treated differently by almost everyone in their lives, including themselves. In summary '*feeling different*' affected every part of the adolescents' lives and was related to their treatment due to their hospitalisations and decreased immunity.

Losing Control

The other aspect of the context of "*conquering the cancer experience*" is '*losing control*'. All of the adolescents in the study attended hospital for varying amounts of time for their treatment which lead them to feel they were not in control of their lives. '*Losing control*' is the category which describes how the adolescents felt primarily when they were in hospital. The dimensions of losing control included 'making decisions', 'feeling trapped', 'feeling in the dark', 'worrying' and

‘feeling exhausted’. These dimensions describe how the adolescents felt while they were hospitalised, which led them to feel that they had lost control of their situation.

‘Losing control’ helps to set the scene for the adolescents while they were

“conquering the cancer experience”.

Making Decisions

One of dimensions of *‘Losing control’* was ‘making decisions’ about their cancer treatment including the type of treatment they would have. Often these decisions were made by their parents and doctors. Having cancer meant that the adolescent felt different because their treatment involved making decisions. These adolescents felt that they should have been involved in making decisions. The adolescents wanted some control in their lives and they felt this was taken away from them because they were not adequately involved in the decision making process. The doctors often only discussed decisions with their parents and not with them. In particular, Eliza found this difficult.

Eliza *...they didn’t tell me what was going to happen
they’d get my parents to decide and I would have
rather that it was my decision.*

Some adolescents had an active role in ‘decision making’. Frank was over 18 years of age at the time of his treatment and attended an adult hospital. He was given the opportunity to have input into decisions about his treatment. However, not all adolescents who attended adult hospitals were given this opportunity. Frank spoke about how he appreciated being able to have an active role in decision making.

Frank *It was good because it gave me an active role in
my treatment other than just receiving it. Um so
yeah it was pretty good.*

Some of the adolescents felt that there were not really any decisions to make as it was either ‘have treatment or die’. ‘Decision making’ involved choices and consequences of choices in relation to their treatment. Sally’s experience reflects this view.

Sally *Um there weren’t very many decisions to make because um they were all pretty bad so you had to pick so yeah.*

Making decisions about their care was important for these adolescents with cancer. They wanted to know what was going on and what choices they had. They felt they had no control over their lives. They felt different, because decision making in this context was something their peers did not have to do. Another dimension of ‘losing control’ is ‘feeling trapped’ which describes how the adolescents felt when they did not have control over their situation during their hospitalisation.

Feeling Trapped

‘Feeling trapped’ is another aspect of the context that describes the adolescents feeling that they would never get out of hospital. The adolescents felt “stuck” in hospital with “no out” in sight and that they had no control over their situation. The adolescents often spent extended periods of time in hospital and Steve described the experience as “worse than prison”. Sally felt the worst thing was “never getting home”. The adolescents did not express that they thought they were kept in hospital unnecessarily, just that they never seemed to get out. Eliza’s father “got in trouble” from the nursing staff when he took her outside for a break and some fresh air. The dimensions of ‘feeling trapped’ were feeling lonely, being bored, and being hurt.

One of the emotions the adolescents experienced when they were ‘feeling trapped’ was loneliness. The adolescents were lonely because they did not have

anyone to talk to in hospital. Loneliness affected the adolescents' perception and ability to cope with their experience. The age of other patients in the hospital ward influenced who they could talk to and how lonely they felt. Eliza was particularly affected by the older patients in the ward she was in.

Eliza *Um... Ok probably the fact that I was kind of with the old dying people! Um... just the fact that it was lonely and boring.*

Loneliness was also associated with boredom in that when they were lonely, the young people did not have anyone to interact with and they became bored.

The adolescents often did not have the skills or the facilities to prevent boredom. This is also explored in the condition of 'hospitalisation' in the dimension of 'available resources'. Joshua and Eliza describe their experience in the following quote.

Joshua *You'd rather someone to play with like cause mums get boring after a while.*

Eliza *... it was lonely and boring. No entertainment and sort of no I don't know mental or physical or anything stimulation.*

Boredom became part of their experience for these adolescents with cancer. Another dimension of 'feeling trapped' was that they were physically hurt, and they could not escape from this. Cancer treatment has sequelae including frequent injections, general anaesthetics and mouth ulcers. Sally felt the effects of her cancer treatment were one of the worst things she had to endure.

Sally *But um I also didn't like the side effects of chemo. And the needles and all the other type of operating things they had to do. Putting me to sleep all the time. Waking up feeling muggy...*

In conclusion the hospitalisation of these adolescents led to them 'feeling trapped'. Ultimately this describes how the environmental aspects of being hospitalised such as being bored or lonely affected these adolescents with cancer.

The emotional aspects of the experience of being hospitalised are reflected in the category of ‘feeling in the dark’.

Feeling in the dark

Often the adolescents were left feeling uninformed when they were hospitalised. This experience included having concerns, and feeling left out of discussions. The adolescents did not know what was going on or what they could do to help themselves. The adolescents felt that improved communication with the medical staff may have helped them feel less ‘in the dark’. Often their parents understood what was going on but they were not able to express this knowledge to their adolescent. When the adolescent felt comfortable asking questions of the nurses and doctors it helped them feel more informed. The adolescents thought the staff needed to understand that they should use age-appropriate language to give information to the adolescents. Some adolescents felt that they were kept up to date with what was going on with their treatment.

Steve was very proactive in regards to his care and felt that he was given enough information about what was happening during his treatment. The following quote described how he managed to feel in control of his situation throughout his treatment. He felt that if he had not asked questions he would probably have felt that he was not informed.

Steve *No I didn't. Because I did write questions down to keep up with everything.*

Eliza was unhappy with how the doctors treated her and thought that they should have discussed her diagnosis and treatment with her, as well as her parents. This meant that she felt uninformed and had no control over her situation because she was not included in discussions.

Eliza *Like my parents asked me what I thought. But I thought the doctors should have asked me. Maybe consulted all of us*

not just mum and dad. I'm the one who has to live with it not my parents and not the doctors.

‘Feeling in the dark’ influenced how the adolescents were able to “conquer the cancer experience”. It affected their lives while they were being treated because they did not know what was happening to them or why. This lack of knowledge relating to their situation led the adolescents to feel worried.

Worrying

‘Worrying’ is a dimension of ‘losing control’ which describes concerns related to treatment, diagnosis, and sequelae of treatment. When the adolescents were worried about something, they felt a lack of control in their lives and that influenced their ability to “conquer the cancer experience”. Joshua found that he did not know what was going to happen when he had finished treatment and this was weighing on his mind.

Joshua *Oh I just want to know if we are going to have keep coming back to get chemo every couple of months and stuff.*

Steve found that he experienced lots of worries while he was hospitalised because he had time to think.

Steve *...certainly is a lot of time to do a lot of thinking.*

Joshua was concerned about the fact that he did not “feel bad” when he was diagnosed. This was emphasised by the way his parents reacted to his diagnosis and the pending treatment.

Joshua *Yeah I just went with.... I didn't really notice... I didn't feel that bad about (the diagnosis)... like they told me stuff and everyone else felt bad.*

Eliza felt self conscious because of the sequelae of her treatment. This was a worry about what was physically happening to her. ‘Worrying’ is an important dimension of ‘losing control’ as it helps to set the context for the adolescents’

experience. Another component of ‘losing control’ for these adolescents was ‘feeling exhausted’.

Feeling exhausted

One of the physical sequelae of treatment for cancer for these adolescents was ‘feeling exhausted’, which affected most components of their lives. Each adolescent was affected differently and they dealt with it in their own unique ways. The adolescents were affected in varying ways including feeling tired, sick and just wanting to sleep. Sally found that she slept a lot throughout her treatment and she describes it below.

Sally	<i>Well I slept most of the time. I was a sleeping person. I think that's how I got over things.... When I was awake I watched a lot of movies. My brain was very tired and I didn't want to do anything.</i>
-------	---

When the adolescents were ‘feeling exhausted’ they were unable to socialise with their friends. Mark found that he could not socialise with his peers because he had no energy.

Mark	<i>You know. I'm all sluggish and I always feel like lying down and. I'm inside lying on the back couch and then they(mum and sister) usually bring me food and stuff as before I'd be able.. and be normal.</i>
------	--

In summary the context of ‘*losing control*’ was significant in the cancer experience. It impacted on the adolescents’ lives and included the dimensions of ‘making decisions’, ‘feeling trapped’, ‘feeling in the dark’, ‘worrying’ and ‘feeling exhausted’. The impact of ‘*losing control*’ describes both physical and psychological issues for these adolescents, providing an insight into what the experience was like for the adolescent.

The context for these adolescents as they conquered the experience involved ‘feeling different’ and ‘losing control’. When exploring the context it is important to realise that each adolescent’s experience is individual, and differed widely from

each other. In analysing these experiences, the emergent categories display the essence of the experience for the adolescent.

Conditions of Conquering

The conditions of “*conquering the cancer experience*” included ‘*hospitalisation*’, and ‘*social supports*’. The impact these conditions had on the adolescent’s experience varies and this can be seen through the dimensions of each category. The conditions can influence the context, processes and ultimately the consequences of the experience. Schatzman (1991) described a condition as a category which influences the processes, although through this research it has become obvious that they can also impact on the context, and the consequences.

Hospitalisation

The category ‘*hospitalisation*’ describes the various ways that the physical aspects of their treatment influenced their experience. The issues discussed in the category of ‘*hospitalisation*’ were issues that the adolescent faced while they were in hospital and had an impact on their experience. These issues included ‘distance from home’, ‘age of others in hospital’, ‘food’ and ‘available resources’. Each of these issues influenced the adolescents in differing ways, depending on what was happening to them at the time. There were a number of ways ‘distance from home’ impacted on the adolescents’ lives, including their ability to socialise, attend school, and have support from their loved ones.

Distance from Home

The adolescents lived varying distances from their treatment centres, as seen in the Table 3.3 on page 38. This distance impacted on whether they were able to go home between treatments, or had to stay in the accommodation available in the vicinity of the hospital. If the adolescent lived further than about a 45 minute drive away from hospital, they were often not allowed to go home, although this was at

the discretion of the adolescent's oncologist. Other factors which influenced whether the adolescent could go home also included the intensity of treatment and the expected sequelae from this treatment. Frank found the distance from home particularly difficult because he lived so far from his treatment centre. Living so far from his treatment centre meant that he rarely saw his friends, siblings or father, which left him feeling isolated.

Interviewer	<i>What were some of the bad bits?</i>
Frank	<i>Um we were so far from home.</i>
Interviewer	<i>How far from home was it?</i>
Frank	<i>Well were actually at x that's about nearly 900 kilometres or something (from his treatment centre).</i>

This distance from home interfered with how often they were able to see their friends and family and how they used their support network. The paediatric and adult hospitals had both positive and negative aspects associated with them.

Age of others in hospital

The age of other patients in hospital was a situational issue the adolescents had to deal with and impacted on the adolescent's cancer experience. The impact of this condition depended on which hospital they attended. Some of the adolescents were treated at paediatric hospitals and had problems with the younger patients in the hospital. The younger children would make noise, play games and also use all the computer game machines. This meant the adolescents could not use the games as tools for 'escaping'. Mark found that the younger children were much too noisy and that they constantly cried, which he found very annoying.

Mark	<i>Um well it could be a bit more sound proof I find the babies are a bit (whinge whinge) all the time and that makes it hard, babies are annoying....</i>
------	--

In the adult hospital environment the adolescents were surrounded by adults who were often much older and who had different expectations of the adolescents behaviour in hospital. In an adult hospital there were rarely age appropriate

distraction tools, and Eliza describes the experience as just ‘unfun and really really scary.’ Eliza also found being surrounded by older adults was very disturbing because she thought most of them were dying.

Eliza *Well I ah... I went to the XYZ (hospital) and it was an adult hospital. So it was probably... it was probably (sic) not as good as it would have been in a children's hospital. Because especially in the oncology ward ...like.. I was pretty much surrounded by old dying people.... and yeah so it was probably an unpleasant experience. It wasn't oriented towards children. So it was like quite plain and unfun and really really scary.*

Most of the adolescents felt that being with other adolescents was a good thing. They wanted to be in a two-bed room with another adolescent rather than in a single room or in a large four-bed bay. Mark appreciated being with another adolescent because it helped to normalise his situation.

Mark *I don't know sometimes ...I like.. like(sic) the other day when I came in for a blood transfusion. I was sitting next to a boy who was fourteen and he was in the next bed it was good to see someone who was going through difficult things as well. So I don't think I'd have too many single rooms.*

The age of other patients definitely impacted on the experience these adolescents had in hospital. They all preferred to be with people their own age. Regardless of whether they attended an adult or paediatric institution, these adolescents found that the age of the people they were hospitalised with impacted on their experience.

Food

Another aspect of their hospital stay was the ‘food’ which also impacted on their experience in differing ways. During their hospital stay food became either a positive or negative experience for these adolescents. They either liked it or disliked it, and sometimes this impacted on their stay by making them worry about

what would happen when the food trolley arrived. Eliza liked the food and it did not have a major impact on her experience.

Eliza *Yeah I'm probably the only person out there who actually likes hospital food.*

When the food was a negative experience for these adolescents it often led to them feeling nauseous or vomiting at the sight of it. Some of the adolescents refused to let the domestic staff bring the food into the room. Parents were helpful here, often reminding staff that their adolescent did not like the food. As oncology patients often lose weight due to the high caloric requirements from their tumour, or as they are recovering from treatment, they are provided with high fat foods such as fried chips and chicken to counteract their weight loss. The adolescents preferred lighter meals and Mark found he could eat the jelly served to him on his tray because they hadn't 'greased it up'. Steve was disgusted with the quality of the food.

Steve *The food is dreadful that's one of the biggest points.*

Available resources

The resources available for these adolescents varied depending on which hospital they attended. The type and quality of the resources also had an impact on their experience. Resources varied from video games and computers, to information about their cancer. Resources influenced the process of escaping. Steve found it difficult because he had to rent a television while in hospital and he felt it should have been provided free.

Steve *I thought it was pretty disgusting that people had to pay to watch public television. That was shocking. At the LMN hospital we didn't have to pay at all.*

Other adolescents found that the resources were inadequate or not appropriate for their age. These resources were important because they had an impact on how the adolescent was able to ‘play’ to ‘*escape*’ their situation.

The ‘*hospitalisation*’ issues these adolescents dealt with impacted on their whole experience. Each of the ‘*hospitalisation*’ issues, ‘distance from home’, ‘age of others in hospital’, ‘food’, and ‘available resources’ affected the adolescent in different ways. These hospitalisation issues could have an impact on the coping strategies the adolescents used during their experience of conquering cancer.

Social supports

Another aspect of the context of ‘*conquering the cancer experience*’ was ‘*social supports*’. The supports available to these adolescents with cancer as they conquered the experience included their family and parents, peers, and staff. ‘*Social supports*’ had an impact on the context (in how they experience their situation), on the processes (how they were able to utilise the processes) and the consequences (due to the influence on the experience of the context and processes). There are a number of sources of ‘*social supports*’ which the adolescents described as influential in their experience. The first of these was their parents and family.

Parents and family

The parents and family played an integral part in the experience of these adolescents with cancer. The parents were a pivotal support mechanism for the adolescents. The adolescents described how good it was to have their parents stay with them. Their parents and family became their primary social network, especially when they were unable to see their friends. Eliza found it difficult because she wasn’t allowed to have her parents stay with her when she slept overnight in the hospital. The hospital said that it was against workplace health and safety rules to let her parents stay. She was finally allowed to have one of her

parents stay the night with her. Other adolescents found that having their parents stay with them was allowed. Steve found that having his parents and family around was a good support and he appreciated the way that family could come at any time and visit him.

Steve *And another good point was they didn't really have visiting hours. That was... you know if the family wanted to they could basically stay there. So you could be surrounded by a network of friends and family if you had thatwhich I know some people did that was good.... yeah.*

This support influenced how they were able to deal with what was happening to them. The adolescents felt more comfortable with their parents present to help them, especially with practical support, for example going to the toilet, or changing bed sheets. Other supports the adolescents valued were their peers.

Peers

Through their experience the adolescents found that they had developed two sets of peers. These peers included the friends they had at school and also the friendships they made through their experience with cancer in hospital or support groups. Due to the experiences of both these groups, the adolescents found that they used each group for different reasons. These adolescents found that their school peers were generally supportive.

The school peers tried to help the adolescents as much as possible but they sometimes struggled. Mark found that his peers were very supportive when he returned to school and he really appreciated this support because he felt weak. However, he sometimes felt they went 'over the top.'

Mark *they're like... oh he's got cancer and stuff like that... sometimes they're a bit touchy like don't bump him. My friends are always being really careful. I suppose.... I was weaker and stuff but I wasn't that weak that they couldn't*

bump me! They were very careful they were protecting me so people wouldn't crash into me.

Other adolescents found that their school peers did not know what to do and in some cases they just did not talk to them at all. Sally found this particularly frustrating and thought that her peers should have made a greater effort.

Sally *I know a lot of my friends when they found out they didn't know what to say to me. You know they were like oh... you know... I didn't want to talk to you because I didn't know what to say. That also makes you feel worse because they don't want to talk to you. So you think that they're against you.... you (sic) know what I mean. Then you're like... oh no one likes me or there going against me just because I have cancer and then you say well you know why don't you find out more about it or someone can tell you.*

Often these adolescents found that their peers acted in a way that they did not agree with, and that this led to them no longer being friends. Eliza found that she now had different values to her friends and decided that she no longer wanted to be friends with them. This happened to many of the adolescents within this group.

Eliza *Um.... they kind of tried to be support but they weren't... um ...they were kind of like the cool group. They sort of like... um probably I didn't see them much when I was sick. I kind of didn't agree with all the things they did. Oh okI just sort of felt like I just had cancer and you guys all want to smoke or you just want to have drugs where I didn't have a choice about whether or not I had the drugs put into me in the hospital. It just made me not have their point of view so I stopped being friends with them.*

Often this meant the adolescents lost contact with previous friends and made new friends. They often turned to oncology support groups specifically for adolescents when this happened.

For these adolescents the oncology support included 'Seize the day', (an organisation run by the Cancer Fund), CanTeen, and Camp Quality. Information about these groups can be found in Table 1.1 on page 11. Involvement in these groups helped the adolescent feel normal because each person involved had

experienced what they had. Sally found that they knew exactly how to treat her and speak to her which differed from her school peers, who struggled with what to say or how to treat her.

Sally *They actually make you feel normal. You know... what I was saying about school and how they don't know what to say and... I think they understand that you don't want to talk about it.... You know.. it's just something that you want to push away and don't think about lock it in a closet or a safe and don't open it.*

Adolescents who did not belong to support groups also found friends within the hospital situation. The adolescents liked to be with people their own age, and often sought out people they had made friends with on previous admissions. Steve found that he had very few friends because he had recently moved to Queensland from interstate. The adolescents found camaraderie at the support groups due to their hospitalisation, as they had similar experiences.

Steve *No. Only a few friend that like... inpatients that I've met there. One guy especially, Richard that I know well and he had his transplant basically at the same time.... and you know we get along really well. Sort of at the same stage we've been sort of knocked back with sickness after sickness.... Of course we understand exactly what each of us each one has been through so yeah but apart from that... No I haven't had the chance to really socialise.*

The adolescents found that their cancer peers were a great support because they knew what to say and what they had gone through with their treatment. The cancer peers did not make these adolescents feel uncomfortable about what was going on. Another source of support for the adolescents was the hospital staff.

Therapeutic relationships

Within the conditions of “conquering the cancer experience” there is the category ‘*therapeutic relationships*’ which describes the care the adolescents received from the staff at the hospital. The staff included nurses, doctors, domestics and volunteer staff, all of who had an impact on the experience of these adolescents

with cancer. Within this category the adolescents described the importance of trusting staff, the staff being supportive, and the staff treating them like friends. However, they also found that the staff did not always understand what the experience was like for them. Each of these issues impacted on the adolescent's experience of cancer. The adolescent's trust in staff impacted on how comfortable they felt during their hospital stay.

When staff developed a trusting and honest relationship and environment for the adolescent, the adolescents began to feel confident in the care they received. Honesty was very important for the adolescents as it meant that they could develop a trusting relationship with the staff. When the adolescents did not have this honesty they were frightened that something might happen that they were not expecting. Through developing trust, the adolescents were able to feel confident that they would have warning of what was happening to them. Mark was shocked and frightened when he was confronted with a nurse wanting to take a blood test without any prior warning. Mark did say that he was very jumpy at this point but that in a trusting environment he may have felt more secure.

Mark *I don't like to be surprised this whole thing were they came in last and said oh we have to get a blood culture from me cause I had a fever that was a bit of a surprise but I suppose they couldn't have warned me before hand.*

These adolescents found that honest straight forward communication helped to develop a trusting relationship. The adolescents also found that the support of staff was important to their experience.

When the staff provided techniques to make their situation better, the adolescent found that the experience was, as Eliza stated, 'bearable'. It assisted the adolescents with coping mechanisms to help improve their situation. These adolescents felt that they could tell the staff (generally nursing staff) anything.

Sally found that this was particularly helpful as she struggled with her cancer experience.

Sally *They were pretty much like your counsellors. You could tell them anything and then they'd be like its ok you can do this and it will help and you'll be alright it's only another couple of times. And things like that.*

The adolescents felt that the staff cared about them and appreciated the staff listening to them. Chris found this particularly useful.

Chris *Oh just would listen and stuff about what you have to say.*

As well as appreciating that the staff listened to them, they also found the staff who treated them as friends were the ones they related to the best. They wanted the staff to discuss what was going on in their lives and ask them what they had been doing. The adolescents found it helped if they did not talk about what was happening within the hospital but spoke about normal life outside the hospital. The adolescents also identified times when the staff had helped, as Steve put it, 'beyond the call of duty' and they really appreciated what the staff did for them. There were also times when these adolescents felt that the staff did not understand what was happening.

Occasionally the adolescents felt that the staff did not understand what it was like to be an adolescent dealing with cancer. The main issues that the adolescents identified were that some staff at times emphasised that their situation was not as bad as it seemed, and they felt staff treated them as a disease and not a person. They also did not want the staff to treat them as if they were going to die. Most of these adolescents struggled with staff not understanding, but in particular adolescents who attended adult institutions.

In conclusion the 'social supports' available for the adolescents varied, and their impact on the adolescents' experience of cancer differed. The adolescents

used these supports at different times throughout the treatment and developed relationships with different individuals through these supports. The supports impacted on the context of the experience in that the adolescents experiences differed due to the support available to them, and how they accessed the support. It also impacted on the processes because these adolescents often relied on their supports of family, peers, and staff to help them realise their coping processes. Ultimately, this impacted on the consequences and outcomes of the experience. This impact differed for each of the adolescents. The way these adolescents dealt with and learnt to conquer their experience was through the processes of '*escaping*', '*gaining control*' and '*seeking new friends*'. The conditions described will have an impact on their ability to develop and utilise these processes.

Processes of 'Conquering the cancer experience'

The processes the adolescents used to conquer the experience of having cancer included the categories of '*escaping*', '*keeping on top of things*', and '*seeking new friends*'. The adolescents used these processes to deal with their experience of being diagnosed and treated for cancer. Each process will now be described using data from the adolescents' interviews.

Escaping

The process of escaping describes the techniques these adolescents used to cope with their experience. The processes included not thinking about what was happening to them by using play as a distraction tool.

Not thinking about it

The escaping technique of '*not thinking about it*' is linked to the context of '*hospitalisation*' and '*feeling in the dark*' (as previously described on page 63 and 60) because the adolescents tried not to worry themselves about what was

happening. Within the category of '*not thinking about it*', the adolescents used the techniques of 'looking to the future' and 'pretending it's not happening'.

'Looking to the future' describes how these adolescents focused on what was going to happen in the future rather than what was happening at the time of their diagnosis and treatment. This is a form of escaping and in doing so they were coping with their situation. The adolescents tried not to dwell on their situation and to pay not too much attention to what they were doing and feeling. Steve and Sally both spoke about hope and how they used this technique. 'Looking to the future' is a way of '*not thinking about it*' as is '*pretending it's not happening*' which is a technique the adolescents used to '*escape*'.

These adolescents spoke about locking the experience up and throwing the key away or pretending that they were not there going through this experience. Sally spoke of wanting to lock away the experience and she described this when talking about wanting to feel normal.

Sally *You know.. it's just something that you want to push away and don't think about lock it in a closet or a safe and don't open it.*

They used this technique to get away from the whole experience and are linked to feeling different. If they pretended that this experience with cancer wasn't happening to them, these adolescents with cancer could pretend they were normal. Frank did this while he was in hospital, he would tell himself that he wasn't there, and that is how he dealt with his experience.

Frank *Mostly just pretended that I wasn't there. Just put it into my head that I wasn't there. That made it a lot easier.*

The process of '*not thinking about it*' was used by most adolescents to deal with many of the issues described within the context of '*feeling different*' and '*hospitalisation*'. This group of adolescents also wanted tools to be able to '*escape*'.

These are described through the category of ‘play’. These tools included distraction tools and the physical environment.

Play

The category of ‘play’ describes structured activities the adolescent participated in to escape from their situation and ultimately conquer the experience of having cancer. Generally ‘play’ involved using age appropriate (where available) distraction tools to escape from their situation. The distraction tools kept them occupied during their hospital stay and were used to combat the experience of ‘feeling in the dark’ and ‘feeling trapped’ described in the category ‘*hospitalisation*’ within the context of “*conquering the cancer experience*”. The use of distraction tools seemed to be gender related. The boys enjoyed computers, computer games and music while the girls found arts and craft, reading magazines and letters more enjoyable. These tools helped to pass the time while they were in hospital. The act of keeping busy helped to keep their minds off their situation and to help stop them worrying about what was going on. Often the staff suggested ways to utilise distraction tools. Once the staff had encouraged the adolescents to use the tools their parents, family and peers often encouraged and facilitated the use of these tools, which links to the condition of ‘social supports’ through the staff, parents, family and the available resources. If any of these supports were not functioning well, the adolescents were not able to ‘escape’. The adolescents also spoke of wanting to access somewhere they could be physically active. Steve wanted a gym so he could ‘kick start’ his body to feel better.

Steve

Also I would have far more like a gym... um because if your up to it a little bit of light exercise goes a very very long way...but you body... um you know realises its got make up and do what it has too, to get better it sort of gives it a kick start maybe.

Frank wanted somewhere to spend the time when in hospital where he could feel away from the hospital. This is a process linked to the category ‘*feeling different*’ as described in the context section of this chapter (on page 53).

Frank Oh I don't know. Probably put an area like were they could just go and get away from everything. And make it pretty colourful the QRS wards aren't very colourful

This form of ‘play’ provides an example of the dimensions of the category, because play is not simply about playing games, but it is about the ability of the adolescent to ‘escape’ from their environment.

‘Escaping’ allows the adolescent to get away from their experience for a while. Generally these play techniques were used while the adolescents were in hospital, which indicates that their experience of having cancer as an adolescent was exacerbated when hospitalised. Due to this hospitalisation these adolescents developed techniques to keep on top of things while they were “Conquering the cancer experience”. They needed to keep on top of things at school as well as issues relating to their condition.

Gaining control

These adolescents used the process of ‘gaining control’ to help them conquer their experience, particularly the context categories of ‘hospitalisation’ and ‘feeling in the dark’. To keep themselves on top of things these adolescents used techniques of ‘keeping informed’ and ‘restructuring their school program’. The techniques used in ‘gaining control’ deal with both their diagnosis and treatment for cancer and their school lives. These processes are needed to conquer the experience of cancer in adolescence.

Keeping informed

To help them ‘keep informed’ the adolescents appreciated the staff giving them information about their diagnosis and treatment for cancer ‘bit by bit’, as it

was necessary. This involved numerous short education sessions and the provision of written information for reading at a later point. Giving the adolescents information about their diagnosis and treatment in short sessions allowed them to process this information. Chris found this very useful to help him absorb and understand what was going on. He also found it useful that the nurses and doctors provided him with both written and verbal information.

Chris *They told you at the start.. like gave you the like... didn't just lay all the stuff in front of you like.. with all the pamphlets and stuff they gave you a little bit at a time. not just one big handful cause.*

Interviewer *And that was good?*

Chris *It was good to give it to you slowly and in bits. It let you read bits and pieces at a time not just all at once.*

When providing with the information the adolescents wanted the information given to them in a clear manner without the use of complex medical terminology that they did not understand. The adolescents found it was easier to understand what was going on if the staff provided the information in a calm and relaxed manner and let the adolescent feel confident in their knowledge. This relates to the condition of 'therapeutic relationships' and trust. If the adolescents did not trust the staff, they would not be able to concentrate on what was going on and absorb the information given to them. When these adolescents were given information about their disease or treatment, they used various techniques to learn.

Learning for these adolescents was a gradual process and continued throughout their treatment. Often the adolescents found that their parents were told about what was going on and provided their adolescent with information. The adolescents found that when their parents told them information it was good, because they could then talk as a family and discuss what was going on. However, they also found that their parents could not answer the difficult or technical questions they often had. Therefore the adolescents wanted to be told by the

doctors what was going on, rather than relying on their parents to tell them information second hand. The adolescents mainly used face-to-face communication to understand what was going on so as to be able to ask questions. They also used books and booklets, but often wanted someone to go through the book with them. Steve found that face-to-face communication was essential and in the following quote he expressed that he wanted the doctors to spend time with him and explain things.

Steve *Um... the best way is face to face communication. If anything sort of dramatic is told or said you're going to remember that from your doctor or what ever.... I think its important for the doctors just to spend I... even if its just another couple of minutes with the patient.... whole ease the mind type thing.*

The adolescents also found that experiencing something was the best way to learn and that the staff often provided more information about the side effects as they occurred. Due to their diagnosis, all the adolescents spent a considerable time in hospital and were not able to attend their school or university. They had to develop techniques to keep on top of things and most of them did this successfully.

Restructuring school program

There were many options for the adolescents when they were 'restructuring their school program'. Sally repeated the year because she felt that she would not be providing herself with the best opportunities in the future if she did not. Others who were at school simply continued with the same class they attended prior to their diagnosis and treatment. Steve was supposed to start university the year he was diagnosed but deferred and was hopeful of returning. In the following quote, he describes his disappointment at not being well enough to attend university.

Steve *...every time... I just got knocked back and back and back I was really disappointed. This put Uni out for longer a way and you know... I think that was pretty disappointing but.... um but yeah so town planning.*

Although all the adolescents said they had missed a lot of school, most of them found that they were able to keep up with their class. The adolescents who attended paediatric hospitals had school teachers who visited them and liaised with their schools to help them keep up with their class. Most of the adolescents were able to successfully conquer the experience of cancer and dealt with their schooling well.

In summary, the adolescents utilised their supports to help them keep on top of things throughout their treatment. The adolescents found that the social supports were important to help them deal with their experience. Keeping on top of things allowed the adolescents to feel in control of their situations and also helped them to feel informed. Throughout their hospital stay the adolescents also developed new friendships to help them deal with their experience.

Seeking new friends

The category of '*seeking new friends*' describes the actions the adolescents used to develop new '*peer supports*' through 'attending support groups' and 'socialising in hospital'. These new friends helped the adolescents feel normal, referring to the category in the context of '*feeling different*'. The adolescents found that their new friends understood how they felt and helped them to feel normal.

Socialising in hospital

The adolescents sought new friends when they were in hospital through socialising with other adolescents who were receiving treatment at the same time. Through socialising, the adolescents were able to feel that what they were going through was normal. There was no formal way for the adolescents to socialise in the hospital so it occurred through the adolescents playing computer games with each other, being placed in the same room with each other, or through talking at

clinics. The support groups provided a formal environment for the adolescents to socialise in.

Attending support groups

Some of the adolescents attended specific support groups for adolescents with cancer. The adolescents who did attend support groups found they were helpful for them when dealing with the context of *'feeling different'*. Support groups provided the adolescents with an environment where they could talk about what was going on if and when they wanted to.

The adolescents used the process of *'seeking new friends'* to help them deal with the context of *'feeling different'*. This process helped the adolescent realise that there were others going through experiences like this and that they were not alone. *'Seeking new friends'* also helped the adolescents to deal with the context of *'hospitalisation'* and *'feeling trapped'* when they felt lonely or bored. In conclusion, the processes the adolescents used helped them conquer their cancer experience.

The processes the adolescents used varied according to their situation and how the conditions influenced their experience. The adolescents all used the processes of *'escaping'*, *'gaining control'* and *'seeking new friends'* in individual ways to help them conquer the experience they had with cancer. Processes are what the adolescents did to help themselves cope with what was happening. They did this successfully, leading to positive consequences from their experience. These consequences reflect the adolescent's ability to conquer their experience.

Consequences of “Conquering the cancer experience”

Consequences are the outcomes of the experience. For these adolescents the outcomes were that they appreciated their lives, and developed new career

pathways. These consequences reflected that the adolescents had conquered their cancer experience.

Appreciating life

The category of ‘appreciating life’ described ways that the adolescent felt different after their diagnosis and treatment for cancer. These changes included being healthier, and feeling stronger. The changes in their outlook made them feel different from their peers, although they did not see this as a negative because they had made the decision to be different.

Being healthier

These adolescents actively sought ways of ‘*being healthier*’ which included eating good food, avoiding drugs and sexual intercourse and being more physically active than their peers. These adolescents felt that this was different to how they felt prior to their diagnosis and was due to the fact that they did not have any choice about the drugs or radiation used to help cure their cancer. This was related to their treatment for cancer and being different from their peers, as they made their own choice about ‘*being healthier*’. ‘*Being healthier*’ was their own choice, and is not forced upon them like their treatment for cancer. However it also makes them different from their peers, which they did not mind. They were happy about their choices even if it meant losing friends. Sally found that she was different from her peers due to her experience and that they made different lifestyle choices. As a result she changed friends, which was not easy to do.

Sally

Um... no I think I'm taking things a lot more seriously. At the moment you know a lot of teenagers taking drugs and.... you know going out and having sexual intercourse and things like that... um and that I don't really do that cause I already I know what the effects are, and what could happen, and how dangerous it is... and how short life could be if you don't take care of yourself. I think I'm a lot more aware.... and a lot more cautious than a lot of other teenagers my age.

This happened to a few of these adolescents because they felt differently about what went into their bodies than their peers. Sally thought that being actively healthier would help her to live longer than, or at least as long as her peers. She felt that her treatment may have caused her to have a shorter life and following healthier lifestyle choices would help her.

Sally *I'm more motivated to be fit and healthy you know and eat healthy. I don't eat junk food. And I think that also preserves me to be (live) a lot longer... or about the same as an average person.*

Through being healthier these adolescents have conquered the experience of having cancer. 'Being healthier' was a choice they made for themselves and this helped them to feel better about themselves. Their treatment gave them the opportunity to turn their lives around and improve their health. They felt that they needed to improve their health because they had treatment forced upon them due to their diagnosis of cancer. Their cancer experience as an adolescent has also lead the adolescents 'feeling stronger' in all aspects of their lives.

Feeling stronger

The adolescents felt stronger after they had finished treatment and had conquered the experience of having cancer. They felt that because they had been diagnosed with cancer they were stronger, not physically, but emotionally. They often spoke about subsequent physical impairments and exhaustion so they did not necessarily feel stronger physically. The adolescents felt that they could stand up for themselves better now that they had conquered their experience with cancer, and that this was as a result of having been diagnosed with cancer. They also felt more mature than their peers. Through conquering their experience the adolescents appreciated their lives more than they would have otherwise.

The experience of having cancer as an adolescent led to them appreciating their lives more than they did prior to being diagnosed. It was almost as if their diagnosis and treatment gave the adolescents an awakening experience. They faced their mortality and conquered it, and as a result are no longer taking their lives for granted. They have had a different experience from their peers and they now find that they appreciate being alive. They showed this through being healthier and feeling stronger. Their diagnosis also led many of the adolescents to develop new career pathways.

Developing new career pathways

The diagnosis of cancer often meant the adolescents could not pursue the career path they had chosen prior to diagnosis. This was due to missing school or physical impairments. The physical impairments included surgery which decreased mobility and the side effects of treatment. Chris was forced to change his plans, because the doctors told him he should not be a panel beater because of fumes affecting his lungs.

Chris	<i>Yeah I wanted to be a panel beater but not now</i>
Interviewer	<i>You don't want to do that now</i>
Chris	<i>No</i>
Interviewer	<i>What made that change do you reckon?</i>
Chris	<i>Oh just all the fumes and stuff and the doctor said I couldn't so.</i>

Other adolescents found that their careers were interrupted just as they had begun. Frank was working in the hospitality industry and found that he had to stop when he was diagnosed with cancer. This led to a complete change in career.

Frank	<i>Well I used to work in the hospitality industry but I've been offered a job with Job Find Queensland</i>
-------	---

These changes in career were forced upon the adolescents although they managed to deal with these changes and develop new career paths. A few of the adolescents had not decided what they wanted to do for a career, although any plans

they may have made could be changed by their diagnosis and treatment. The adolescents managed to conquer their experience through changing career pathways, even when obstacles were placed in their way.

In summary, the consequences of conquering their experience highlighted the adolescents' resilience in the face of adversity. They had taken a 'bad' situation and turned it around into a positive experience. This experience has led them to develop a maturity beyond their years due to their brush with their mortality. Ultimately they have conquered their experience of having cancer as an adolescent.

CONCLUSION

In conclusion, this chapter presented the findings of the study as reflected in the theory of "conquering the cancer experience". The key findings were, that being diagnosed with cancer as an adolescent is difficult, that adolescents use many techniques to cope with their situation, and that each adolescent's experience is unique. All adolescents in this study identified that there was ultimately a positive outcome from their journey. The next chapter will discuss these key findings in relation to current literature and consider implications for nursing practice.

CHAPTER 5: DISCUSSION

INTRODUCTION

This chapter will discuss the findings of the study in relation to other research in the area. The substantive theory “*conquering the cancer experience*” (CCE) was described in depth in Chapter Four. The literature review in Chapter Two was undertaken prior to the study and according to grounded theory principles, was used only to support the need for the study. Further literature and research on adolescents with cancer has been accessed for this discussion and will be incorporated with the literature previously reviewed to discuss the findings of this study.

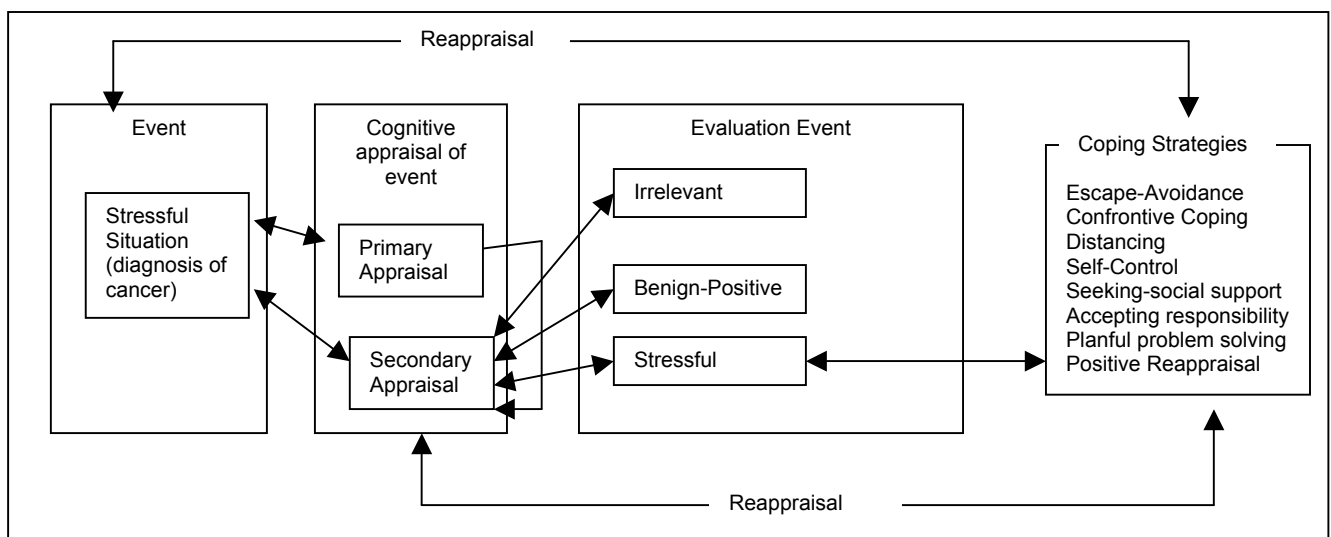
The diagnosis and treatment for cancer was a life-changing event for the adolescents in this study. In response to their experience, they developed strategies to help them cope. The cancer experience was very difficult for all the adolescents in the study, although ultimately they had positive outcomes from this challenging event in their lives. These findings are supported by Ritchie’s (2001b) study of self esteem and hopefulness in adolescents with cancer.

“*Conquering the cancer experience*” details how the participants in this study dealt with being diagnosed with cancer while journeying through adolescence. The coping strategies used by the adolescents are similar to those described by Lazarus and Launier’s (1978) theory of stress-appraised events. To further the understanding of coping strategies used by adolescents with cancer, this chapter will discuss factors that influenced their coping, and how the cancer experience changed the adolescents. This chapter will also discuss aspects of the study’s findings in relation to Lazarus and Launier’s coping strategies. The discussion draws conclusions and leads to recommendations for practice. The chapter also discusses the implications for nursing practice, further research and education, and the limitations of the study.

COPING AND STRESS

Lazarus and Launier's (1978) theory of stress appraised events is well cited in literature and correlates well with the CCE theory of adolescents with cancer developed in this study. Lazarus and Launier's theory explores why people appraise particular events as being stressful, how these events impact on their lives, and how they respond to this stress. Lazarus and Launier's theory of stress-appraised events views a person's experience of stress and coping as a journey of cognition, perception, and transaction. Stress is a dynamic event that changes depending on the environment, the individual's perception, and their previous coping mechanisms (Lazarus & Launier). Figure 5.1 displays this process diagrammatically, demonstrating the relationship between the variables.

Figure 5.1 - Lazarus and Launier's stress appraised event theory



(Adapted from Lambert, Lambert, & Gugino, 1997 p. 76)

Central to Lazarus and Launier's (1978) stress appraised events theory is the process of cognitive appraisal. Lazarus and Launier use the term "cognitive appraisal" to describe the process a person uses in assessing an event, while taking into consideration their overall well-being, coping ability and the available alternatives. Lazarus and Launier describe primary and secondary forms of cognitive appraisal.

Primary appraisal involves the individual assessing the situation they are in and evaluating how significant this is to their well being. Secondary appraisal involves the individual assessing the situation they are in and evaluating how significant this is to their available coping mechanisms. Primary and secondary appraisal can occur concurrently and are important to the person's understanding of an event. The individual reappraises their situation throughout their experience. This is demonstrated in Figure 5.1 (page 86) through a feedback loop. As each individual appraises their situation they come to one of three conclusions or evaluations of the event. These are that the threat is irrelevant, benign-positive or stressful. Only a stressful appraisal requires action and occurs when the individual assesses the situation as having the potential to negatively impact their well being (Lazarus & Launier, 1978). This action results in the individual implementing coping strategies to deal with stressful events.

Using Lazarus and Launier's (1978) theory, Folkman et al. (1986) described eight coping strategies that individuals use to manage stressful events. These are, escape-avoidance, confrontive coping, distancing, self-control, seeking social support, accepting responsibility, planful problem solving, and positive reappraisal. The adolescents used some of these strategies in coping with their experience and this will be further explored. The Folkman et al. coping strategies are presented in Table 5.1 (page 88) with accompanying explanations.

Lazarus and Launier's (1978) theory of stress appraised events was developed in an adult environment. It has however also been used successfully in studies with adolescents including Kyngas et al.'s (2001) study of adolescents coping with a cancer diagnosis and Mazurek and Alpert-Gillis's (1998) study of the coping of critically ill young children and their parents. Therefore, it has also been adapted for the discussion of this study.

Table 5.1 - Folkman et al.'s eight coping strategies

Coping Strategy	Explanation
1. Escape-avoidance #	The individual uses positive thinking and changes in behaviour to avoid or escape from their situation.
2. Confrontive coping	The individual uses aggressive behaviour to change their situation often behaving in a hostile manner and participating in risk taking behaviour.
3. Distancing	The individual detaches themselves from their situation, which reduces the significance of what is happening to them
4. Self-control #	The individual tries to control their actions and emotions.
5. Seeking social support #	The individual is searching for support, emotionally, tangibly and to provide information
6. Accepting responsibility	The individual realises they have a role in problem they often try and put things right.
7. Planful problem solving #	The individual attempts to alter their situation through solving problems
8. Positive reappraisal #	The individual creates a positive viewpoint on their situation. There can also have a spiritual element to positive reappraisal where an individual finds meaning from their experience.
# = Coping strategies used by the adolescents in this study.	

Source: (Folkman et al. 1986).

The following example uses this process of Lazarus and Launier's (1978) theory of stress-appraised events, in the scenario of an adolescent girl who discovers a mass in her breast. Her primary appraisal of the situation identifies that she has a firm and immobile lump in her breast. She then assesses this lump's implications on her life. She may make three evaluative choices as a form of action. She may ignore the lump and believe it is related to her last period (irrelevant appraisal), she might ignore the lump as an indication that her breasts are getting bigger (benign-positive appraisal), or she may become highly distressed at the thought she may have potentially fatal breast cancer (stressful appraisal). In response to the stressful appraisal, she may decide that there may have already been damage to her breast, which is a harm-loss response to a stressful appraisal. Secondly she may decide that she needs the breast removed, which is a threat response to the stressful appraisal, or thirdly she may think that she will need the lump removed, which is a challenge response to the stressful appraisal. In response to this stressful event, the adolescent may use a variety of

copied strategies to help her deal with this situation (adapted from Lambert, Lambert, & Gugino, 1997, p.76).

In summary, the experience of being diagnosed with cancer is very stressful and the use of strategies to deal with this stress assisted adolescents to cope with their experience. The coping pathway set out by Lazarus and Launier (1978) clearly describes the process experienced by the adolescents in this study. The factors that influenced their coping and the life changes caused by their coping will be discussed in relation to the CCE theory and other relevant research on adolescents with cancer and adolescent coping.

FACTORS INFLUENCING COPING

The adolescents felt that there were certain behaviours that the staff could use to help them influence their ability to cope with their experience. There were a number of factors related to this, including the adolescent's relationships with staff, hospital environment, community factors, and physiological factors. Each of these issues will be discussed, in relation to current research, leading to recommendations for practice to help enhance the coping mechanisms of adolescents with cancer.

Relationships with Staff

The relationship adolescents had with the staff affected their ability to cope with their situation. The adolescents developed relationships with the staff at the hospital although they stated that there were aspects of these relationships that could be improved. This section on relationships with staff includes developing relationships, communication and care related decisions. These topics will be discussed in relation to current research and will provide recommendations on each topic discussed.

Developing Relationships

Generally, the adolescents in this study found that they appreciated the staff at their treatment hospital because they treated them well. The adolescents discussed

how they preferred staff that treated them like friends, because it helped them to cope. This included talking about the staff's personal lives as well as staff asking the adolescent about their life outside of hospital. The adolescents identified that developing a relationship with the staff helped them to cope with their situation. This is supported by Dunsmore and Quine's (1995) study of adolescents with cancer and their informational, support, and decision-making needs. They identified "professional friendship" as a technique that facilitated communication between nurses and adolescents. "Professional friendship" is characterised by staff behaving as a friend for the adolescent through behaviours such as displaying a sense of humour, recognizing the adolescent's individuality and also some disclosure about the staff's personal life. Dunsmore and Quine's study therefore correlates very closely with the findings of this study. This form of relationship illustrates how the adolescents used the coping strategy of seeking-social support.

While the "professional friendship" as described in Dunsmore and Quine (1995) has many positive effects, it may also have a negative impact on the patient and staff because it potentially leads to the blurring of professional boundaries. Whelan (2003) also discusses the potential for blurring of professional boundaries when caring for adolescents with cancer. If professional boundaries are not maintained, inappropriate attachment may occur which could lead patients to think of staff as friends, leading to unrealistic expectations of the relationship. In extreme cases, this type of relationship could even lead to a sexual relationship. This emotional attachment may interfere with the nurses' objectivity and judgment when caring for the patient (Nelson, et al., 1999). The Queensland Nursing Council has developed guidelines on professional boundaries to ensure that over involvement and under involvement do not occur. These boundaries help the nurse to provide safe and helpful

care to the patient (QNC, 1999). Professional boundaries are also supported by the ANCI code of ethics for nurses in Australia (ANCI, 2001).

The nurse-patient relationship can play a very important role in a patient's recovery. However, the relationship should always be a therapeutic one. A therapeutic relationship is different to a social relationship, because although it involves being emotionally available to the patient, there are clear boundaries in place. The mechanisms of debriefing and support of the staff help them to maintain these boundaries. There are professional boundary policies in most hospitals, which are designed to help protect staff from inappropriate emotional attachment to patients. Breaching professional boundaries has led to problems for both staff members and patients. It can be a particular problem when dealing with patients over several months to years because intense relationships can potentially develop between nurse and patient (Baron, 2001).

Professional boundaries are set in place for the purpose of preserving the therapeutic relationship. This is highlighted by Riley (1998), who discussed a situation where a nurse discussed drug taking and other recreational activities with an adolescent with cancer. This led to the adolescent losing trust in the nurse's ability to care for him (Riley). When caring for adolescent's with cancer, it can be difficult to maintain a professional relationship. This can be exacerbated if the patient is a similar age to the nurse (Riley) or the age of a nurses' children. Therefore caring for adolescents with cancer requires the nurse to develop techniques so that they are able to appropriately care for the adolescents while maintaining a professional relationship. These techniques may include debriefing with a counsellor, or support from the peers and work colleagues.

The difference between a professional relationship and a personal relationship is that a professional relationship requires the staff member to set limits on the amount

of disclosure and attachment that develops in the relationship. The nature of the relationship depends on the professional, and can differ from patient to patient, but requires some insight from the professional into the aims of the relationship (Baron, 2001). Baron suggests that staff discuss situations that may seem to be crossing professional boundaries with professional peers. This helps the staff member to redirect their relationship with the patient. Wilson (2001) writes that reflection on practice can help the nurse to realise inappropriate relationships, but it cannot repair any damage caused by the relationship. Ultimately, it is important to remember that the staff member is there to provide the best healthcare for the patients, and this is impossible without maintaining a professional relationship.

Communication

The style of communication used by staff with adolescents can affect the effectiveness of their communication and relationship. Honesty, trust, and respect for the adolescent enhance communication. Ferri and Veroneau (1998) support this view and recommend that staff exhibit honesty, trust, and respect within the relationship. Trust is identified as a component of a healthy nurse-patient relationship (Ritchie, 2001). In developing a trusting relationship with adolescents with cancer, the nurse gains an understanding of the adolescent's behaviour from their perspective (Ritchie). This supports the finding that the adolescent's desire for nursing staff to talk about their lives and explore the adolescent's lives outside of the hospital helps them to cope. In addition, McDonald (2001) has indicated that telling stories about how other adolescents coped with their experience was a useful technique to encourage hope. Encouraging hope is related to the coping strategy of positive reappraisal. McDonald also encourages truthfulness in any discussion with adolescents. Honesty, truth, and respect are developed through using the truth in communication. These findings are supported by Dunsmore and Quine (1995) who identified that the adolescents found

honest and straight forward communication very important. Ljungman et al. (2003) found that written information was the most useful form of communication, which is similar to the CCE study. Therefore, communication style use can impact on the adolescent's ability to cope with their experience.

The adolescents in this study did not discuss the importance of nursing staff being knowledgeable about their treatment. This contrasts with Fagerstrom, Eriksson, and Endberg (1998), and Dunsmore and Quine (1995) who identified that patients wanted staff to be knowledgeable and to portray confidence when caring for them. The findings in this study may have differed from the Dunsmore and Quine and Fagerstrom et al. studies due to the differences in the research questions. Dunsmore and Quine investigated the informational needs of adolescents with cancer, while Fagerstrom et al. studied the perceived caring needs of patients with patients aged between 15 and 98. By contrast, this study investigated the coping strategies of the adolescents. The research question in these three studies as well as the differing methodologies may have impacted on the outcome.

It is therefore recommended that staff have an appropriate arena for debriefing when working with adolescents with cancer. This should be individualised to each staff member, taking into consideration his or her preferences and should be aimed at helping to prevent burnout. Education of staff caring for adolescents with cancer should also include topics such as the development of an honest, trusting, and respectful environment. This should occur through various means including inservice, presentation of findings at conferences, workshops, and posters.

Care related decision making

Decision-making involves the coping strategy of self-control. The self-control coping strategy describes the adolescent's attempt to have control over themselves and their environment (Folkman, et al. 1986). The adolescents in this study wanted to be

involved in all decisions regarding their care, including discussions about their diagnosis, care and treatment. The adolescents who were involved in decision-making appreciated being included by the nursing and medical staff. Dunsmore and Quine (1995) also found that adolescents with cancer wanted to be included in decision-making processes. The adolescents in this study did not want to be solely responsible for their treatment decisions, but also wanted their parents to be involved. This desire for parental involvement is probably due to their developmental stage, because as adolescents they are developing independence while still relying on their parents for support. This finding regarding parents' involvement is also supported by the research conducted by Dunsmore and Quine (1995) and Haddad (2002). Additionally the SIOP working committee on psychosocial issues in paediatric oncology support (SWCPIPOS) endorse the inclusion of adolescents in discussions about treatment. However, they also note that parents have a legal responsibility for the health of their child, until the child is of legal age for decision making. This legal age varies by country (Spinetta, et al., 2003). According to Morgan (2003) the Teenage Cancer Unit (TCU) at the St James University Hospital, Leeds, actively involves adolescents in discussions about their diagnosis and treatment. One of the techniques used to assist the adolescents with their decision-making is to give them a transcript of important conversations for later review. The TCU considered that transcribing these conversations to be very useful, however there has been no research to evaluate its effectiveness from an adolescent's perspective. This procedure is recommended by the SWCPIPOS (Spinetta, et al., 2003) and is supported by Ljungman et al's (2003) finding that written information was the most effective form of communication.

It is therefore, recommended that adolescents with cancer be offered the opportunity to be involved in decision-making regarding their care, with the support of

their parents. Adolescents should be included in discussions with their medical staff and invited to ask questions as they arise.

In summary, the adolescents in this study discussed similar needs to those in other studies. They wanted to develop a “friendship” with the staff and an honest and trusting relationship and be involved in decision-making about their care. The development of the recommended education resources would help to improve staff’s ability to communicate with adolescents with cancer. It is also recommended that staff caring for adolescents with cancer be provided with education about appropriate communication techniques, and the ability to debrief regarding caring for adolescents with cancer. Adolescents can have a more positive outcome from their experience through active participation in decision making, feeling secure about their medical treatment, and having positive interactions with staff.

Hospital environment

The hospital environment differed for each of the adolescents in this study. However, each agreed that their environment was not appropriate, regardless of where they were hospitalised. The issues that the adolescents considered the most frustrating part of hospitalisation were room sharing, and lack of access to distraction tools. Each of these will be discussed below.

Room sharing

Involving adolescents with cancer in decisions about their treatment should also involve asking them about their hospital room preferences. In this study most of the adolescents stated they preferred to be in a double room, or a single room in hospital if one was available. Miller, Friedman and Coupey (1998), in their study on adolescents with surgical, medical and gynaecological illnesses, used a questionnaire to study both adolescents in hospital, and those who had not been admitted to hospital, on their room sharing preferences. The authors identified that adolescents preferred to

be in a single or double room rather than a larger room with more beds. However, Enskar, Carlsson, Golsater, and Hamrin (1997) who studied symptom distress and life situation in adolescents with cancer, found that the adolescents preferred a single room over a double room. These results differed to this study's findings that sharing a room with another adolescent was the preferred option. This is supported by Hutton (2002) who also identified that Australian adolescents preferred a double room to a single room. Miller et al. recommended asking the adolescents about what they wanted regarding room allocation on admission to a ward. Giving adolescents the opportunity to make a decision about their room gave them some control over their environment, which facilitates the coping strategy of self control, where the adolescents need to have control over their environment (Folkman, et al. 1986).

Therefore, it is recommended that adolescents with cancer be allowed some control over their environment where-ever possible, which would include being asked about their preferences. The adolescents should also be given the opportunity to bring items from home to help make the hospital room environment more personal and friendly.

Distraction Strategies

When hospitalised, the adolescents in this study used distraction strategies to help them escape from their experience, included watching TV or videos, playing games, reading books or magazines or listening to music. These distraction strategies acted as a diversion to help the adolescents cope with their situation. The category of 'escaping' reflected data on the lack of appropriate distraction tools. The distraction tools they preferred varied from computer games and magazines to being able to talk to their friends via the internet or phone. In both the paediatric and adult environments such tools were either not available or not suitable for their age.

Distraction strategies have been used successfully in previous studies to help adolescents cope with their painful procedures and the experience of hospitalisation. The adolescents in this study mainly used tools such as video games, videos and magazines. Claflin and Barbarin's (1991) study of children and adolescents with cancer and information disclosure identified that adolescents used behavioural distraction techniques such as watching TV and reading. They also identified that adolescents were able to use cognitive strategies as distraction mechanisms including telling themselves that the treatment was good for them or that it would be over soon. Claflin and Barbarin's research correlates very closely with the findings of this study.

Enskar et al. (1997) identified that equipment such as television, videos, and games were useful to help pass the time. The appropriateness of the distraction tools for the individual was important as inappropriate tools were ineffectual. Schneider and Workman (2000) found that the use of virtual reality tools was very successful in distracting adolescents while they were receiving treatment for cancer. Virtual reality tools are a complex form of a computer game requiring specific equipment. Unfortunately, the cost of some of these distraction tools can be prohibitive (see Table 5.2). Adolescents in the CCE study spoke about television, video, and computer games, which are also expensive, however were very important to help the adolescents in this study cope with their situation.

Table 5.2 - Price comparisons for distraction tools.

Distraction Tool	Price for tool	Price of games, CD's etc.
Television	\$250-\$900	N/A
Video Player	~\$160	\$20-\$35
DVD Player	\$80-\$190	~\$30
CD player/radio	\$80-\$150	~\$30
Nintendo/Sony	\$200-\$350	\$50-\$100
Computer	\$1500-\$2000	\$50-\$98
Virtual Reality Tool	\$1300-\$16000	\$40-\$60

(Sources: Chandlers, 2004; Virtual Reality, 2004; R. Lucas, personal communication February 7, 2004)

Through the use of distraction tools the adolescents utilised the coping strategy of escape-avoidance (Folkman, et al. 1998). Therefore, the types of distraction tools available for adolescents with cancer impacts on their ability to cope with their experience. It is recommended that age appropriate distraction tools be available for hospitalised adolescents. It is important that appropriate distraction tools are available, including television, videos, computer games, and magazines. These should be age-appropriate, with M classified videos and computer games and adolescent focussed magazines provided.

School

School is an important component of the adolescent's development to adulthood. Adolescents in this study who attended paediatric hospitals had access to schooling, however the adolescents who were admitted to adult hospitals did not. The adolescents' regular school also played an important role in their schooling while they were hospitalised.

Most of the adolescents in this study were able to continue in their same class as when they were diagnosed with cancer. Despite the fact that they had missed a great deal of their education, they were still able to attain reasonable results after they finished treatment. This was also a finding of Enskar et al. (1997) and Claflin and Barbarin (1991) who identified that an adolescent's school work was not seriously adversely affected by hospitalisation. The adolescents did however miss the social contact of school more than the younger children in the study, which correlates with their developmental age and the importance of peers in their lives. Griffith and Hart's (2000) study of the characteristics of adolescent cancer survivors who pursued post secondary education, found that their teacher's lack of knowledge about cancer could interfere with the adolescent's ability to cope with their situation. Enskar et al., Claflin and Barbarin and Griffith and Hart's studies correlated with the CCE study's findings

that absence from school due to treatment did not seem to adversely affect the adolescents' ability to continue with their education.

It is a recommendation of this study that all hospitalised adolescents with cancer have access to school, through email, telephone, and fax. Liaison between the adolescent and their regular school should be facilitated to promote social interaction with their peers. It is possible to organise videoconferences with school friends through most hospitals in Queensland. Videoconferences allow the adolescents to see each other and communicate, and have been used successfully at the RCH to allow an adolescent to talk to their friends some distance away.

In summary, the hospital environment impacts on the adolescent's ability to cope with their experience. It is recommended that adolescents with cancer be allowed some control over their environment where ever possible, have access to appropriate distraction tools, access to school, and liaison with their peers. These recommendations will help prevent the adolescent feeling out of control and will encourage the adolescent to feel secure in their environment.

Community Factors

The adolescents' ability to cope with their experience was influenced by the support available from their community, which included family and peers. The geographical situation of the adolescents affected the availability of these supports. The impact of these supports on the adolescent's ability to cope with their experience will be discussed further here.

Distance from treatment centre

The distance the adolescent lived from their treatment centre impacted on the support available from their family and peers for some of the adolescents involved in the study. The distance an adolescent lived from their treatment centre, often resulted in less support being available to them. When coping with problems related to

distance, the adolescents used the coping strategies of self control, seeking-social supports and planful problem-solving. The self-control coping strategy describes the adolescents' attempt to have control over their environment. The coping mechanism of seeking social supports describes the adolescents' search for normality, and the coping mechanism of planful problem-solving describes the adolescents' deliberate efforts to try and change their situation (Folkman, et al. 1986).

Research into the impact of being treated away from home has been conducted in Australia. However, Davis, Girgis, Williams, and Beeney (1998) studied women with breast cancer who lived in rural and remote areas of New South Wales and South Australia. In this Australian study, 55 percent of the participants needed to travel more than 200 kilometres for treatment. It was identified that being treated away from their home town put additional stresses on a person with cancer. These included a lack of social and practical support, lack of information about travel assistance, disruption to family life, and disruption to work. These issues were similar to those experienced by the adolescents in this study, which indicates that further research on the impact of distance for patients being treated for cancer is needed to understand how distance affects the patients experience with cancer. McGrath and Segueria (2000) identified that being treated away from your home town added significant financial burdens on the family. However, the adolescents in this study did not discuss the financial burden of being treated away from home.

In Queensland, there are only two paediatric oncology units, both of which are situated in Brisbane. Adults are generally treated in either Brisbane (there are many hospitals in Brisbane that treat adults with cancer) or Townsville. Queensland Health allows adolescents who are younger than 18 to be accompanied by one parent when travelling for treatment. This means that if both parents or any siblings are needed to be at the treatment centre, the parents are required to pay the travelling expenses.

Adolescents who are 18 or older are considered adults and no one is funded to travel with them to their treatment centre. This was a particular problem for one adolescent in this study, as he wanted his mother there to support him. He lived approximately 1000 kilometres from his treatment centre. The families of adolescents who were treated outside of their local area often found that they had financial difficulties due to this. Simple options to help solve these issues would be to fund travel and to allow for weekend leave. Unfortunately, this would place significant extra financial burden on the health system. Adolescents who are treated at the RCH are discharged as soon as they are well enough to be treated as an outpatient. Adolescents who live more than 50 kilometres from the treatment centre are often not permitted to travel home when they are being treated as an outpatient, because they may suffer life-threatening complications from their treatment. Therefore, travel home is restricted to periods in their treatment when they are unlikely to become unwell. It would be negligent to suggest recommendations which are potentially life threatening for the patient, although they would be ideal and would improve the adolescents' ability to cope with the experience. Therefore, it is recommended that adolescents have access to phone or email to communicate with their family if they are being treated away from their hometown. It is also recommended that adolescents be allowed to travel home as frequently as possible, taking into consideration their physical state or potential physical state in the time they will be away.

While families are away from home, support organisations such as the Leukaemia Foundation and the Children's Leukaemia and Cancer Society (See Table 1.1 page 11) can provide accommodation for families close to the hospital at no cost, and offer other supports such as cars for families from outside the local area. It is recommended that families should be encouraged access support groups and to attend

camps, morning teas, and information sessions organised by the support groups listed in Table 1.1 (page 11).

Family supports

Most adolescents in this study relied heavily on their immediate and extended family members for physical and emotional support. If an adolescent is treated away from their hometown, their available family support is reduced to only one parent due to funding constraints. This has a significant impact on the adolescent and their family.

Their reliance on family supports displays the adolescent's use of the coping strategy seeking social support. The adolescents in this study found that their family was a great support to them while they were receiving treatment. This finding is supported by research conducted by Enskar et al.'s (1997) study of symptom distress in adolescents with cancer. However, Enskar et al. also identified that adolescents who were very ill for extended periods craved privacy and found it difficult having their parents present for such a long time (Enskar et al.). In contrast to this study and Enskar et al., Gauvin, Vandai, Mercer, and Bradet (2002) found that relatively short admissions to hospital have limited impact on the adolescent's need and dependence on family support. The participants in Gauvin et al.'s study were adolescents who were undergoing corrective back surgery. These studies have identified that family support is very important for adolescents with cancer but needs to be balanced with the adolescent's developmental needs.

It is a recommendation of this study that the adolescent's family be given unrestricted access to the adolescent while they are in hospital. The adolescents should also be given control as to limiting the number of visitors they receive, in order to maintain their privacy.

Peer Supports

An adolescent's peers are an important part of their social development. Separation from their peers during cancer treatment can be difficult and lead adolescents to feel different at a time when they desperately want to be like everyone else. The amount of time spent in hospital affects adolescents' contact with their peers, and as discussed previously, results in limited avenues for conversing with peers while hospitalised. Often adolescents find that support groups for adolescents with cancer are useful to overcome this. The adolescents used the coping strategy of seeking-social support through using their peers and support groups to help them cope with their experience.

The adolescents in this study identified support groups specifically developed for adolescents with cancer as useful. Stewart et al. (1997) found that individuals gain support from sources with similar conditions to themselves. An adolescent with cancer would prefer to seek support from another adolescent with cancer rather than an adolescent with another chronic disorder. The importance of support groups was also identified by Enskar et al.'s (1997) study of symptom distress in adolescents diagnosed with cancer. Yalom (1995) found that support groups offered the opportunity for hope, a sense of normality, sharing information and the opportunity to learn as well as an opportunity of modeling appropriate behaviours. Support groups provide the adolescent with the opportunity to discuss and share their experiences with others who have undergone similar experiences, and are therefore empathetic.

The adolescents' peers are important in their social development and separation from them can be very distressing. In a study on emotional support for adolescents with cancer, Ritchie (2001c) identified that adolescents use their peers as a form of emotional support. Many of the adolescents in this study found that they were separated from their peers for long periods. Hodges, Graham-Pole, and Fong (1984) identified that peers of

adolescents had positive feelings about the adolescent with cancer. This study correlates well with the current study in that most of the adolescents found their peers helpful. Enskar et al. (1997) identified that when most of the adolescents were diagnosed and treated for cancer, they lost contact with peers. This was also a finding of this study. In Hodges et al.'s (1984) study only 14 percent of peers visited their friends at home when they were absent from school. This lack of contact with their peers may have reduced the support available for the adolescent with cancer when they were away from school. The adolescents in this study found that at times they had trouble maintaining friendships with peers.

The adolescents in this study found that if their peers were aware of their situation then they were better able to cope with the situation. This was also shown in studies by Hodges et al. (1984), Enskar et al. (1997), Griffith, and Hart (2000) that identified that it was important for peers to be informed about what was happening to the adolescent with cancer. Lack of information may lead to confusion and the peers not knowing how to act. Rynard, Chambers, Klinck, and Gray (1998) studied the return to school of children with cancer and found that it is important to educate peers about cancer and its effects on the affected child. It would seem that keeping the adolescents' peers informed about the adolescents' condition is important to maintaining their peer interaction.

It is therefore a recommendation of this study that peers should be included in the patient's support network, which links to their social support requirements. It is recommended that staff encourage visits, phone and email contact with peers. With the consent of both the adolescent and their parents, education should be provided to the peers by either a liaison nurse from the hospital, or a teacher from the school, in order to help them understand what is happening.

In summary, the adolescents in this study identified that the supports they had were a very important part of their experience. These supports were influenced by their distance from their treatment centre and included their family and peers. The recommendations made for community factors should help to improve the adolescent's ability to cope with their experience.

Physiological Factors

The adolescents in this study spoke frequently about their fatigue and the food provided to them when they were in hospital. These physiological factors impacted on how the adolescent felt and coped with their situation. The physiological factors of caloric requirements and fatigue associated with treatment have been discussed in depth in previous research (Berger, 2003; Curt & Johnston, 2003; Fletcher & Bottomley, 2003).

Caloric requirements

The caloric requirements of people being treated for cancer are higher due to factors such as tumour growth and the effect of their treatment (Guenter, Ferguson, Thrush & Coble Voss, 2002). Most of the adolescents in this study found the hospital food unappetising, which reduced their intake and impacted on their ability to maintain body weight. This is significant because malnutrition occurs in between 40 and 80 percent of all cancer patients (Mulligan & Bloch, 1998). Guenter et al. state that up to 20 percent of deaths in cancer patients can be directly related to malnutrition. There are a number of causes of malnutrition in cancer patients including anorexia, changes in metabolism (Mulligan & Bloch), and tumour growth (Guenter et al.). Anorexia is generally caused by cancer treatment, which causes damage to the rapidly dividing cells of the gastro-intestinal tract, painful mucositis of the mouth and gastro-intestinal tract, reduction in saliva production, and alterations in taste (Guenter et al.). According to Mulligan and Bloch (1998), the process of change in the metabolism of carbohydrate,

lipids, and proteins of a person undergoing treatment for cancer is not fully understood. The tumour itself uses energy to grow and can cause malnutrition. The tumour produces pro-inflammatory cytokines and proteolysis-inducing factors which increase the individual's caloric requirements. Simply increasing the individual's calorie intake will not improve their nutritional status in this instance (Guenther et al.).

Seeking options for better food when in hospital shows the adolescents utilising the coping strategy of planful problem solving. The coping mechanism of planful problem-solving describes the adolescent's deliberate efforts to try to change their situation (Folkman, et al. 1986). The adolescents in this study found that the food provided to them in the hospital was unappetising, and many thought that they would have starved if their parents had not provided them with food. McGrath's (2002) research into adult cancer patients supported these findings. The RCH and RBH have a kitchen with facilities for parents to prepare food, and this is well utilised. The adolescents in the RCH are all reviewed by a dietician, who organises for different food items to be brought up on their tray. However, the adolescents often said they preferred "mummy's cooking".

The nutritional status of an individual with cancer is important in their overall survival and the provision of adequate nutritional options would appear to be important. Therefore, it is recommended that there should be facilities such as a kitchen with a stove and microwave oven for parents and family to be able to prepare nutritious and appetising meals to the adolescent's unique tastes and family patterns.

Fatigue

Fatigue impacted on most of the adolescents in this study and was directly related to their treatment. The adolescents were often unable to participate in various activities with their peers due to fatigue. Fatigue impacts differently on each adolescent's ability to cope with his or her situation. Most of the adolescents in this

study found that it interfered considerably with their social life. This is supported by the findings of studies by Claflin and Barbarin (1991) and Hockenbury-Eaton et al. (1998). Winningham et al. (1994) which identified that fatigue can be debilitating and is often exacerbated by the adolescent being encouraged to rest and minimise activity. Winningham et al. suggests that the patient should participate in some form of physical activity to help them recover from their fatigue. Keats, Courneya, Danielson, and Whitsett's (1999) research into physical activity and psychosocial well being found that adolescents who were able to continue structured sporting activities during their treatment suffered less psychosocial distress, which may help them cope with their situation. The adolescents in the current study wanted an area for physical activity as a distraction tool. This finding is supported by Hutton's (2003) study into adolescent patients and shared space in the ward area; these adolescents wanted somewhere to be active away from the ward environment. This area could also be used to help relieve the effects of fatigue.

It is therefore a recommendation of this study that staff be educated about fatigue and its effects so that they can educate adolescents and parents about the importance of physical activity. Staff should also encourage adolescents to participate in some form of light physical activity when ever possible. The provision of an activity area close to the ward would help to encourage the adolescents to be active. The activity area could be used by the adolescents alone or with their physiotherapists or occupational therapist to help prevent fatigue.

In summary, there were two aspects of the adolescents' experience that related to physiological issues. These were caloric requirement and fatigue. These aspects impacted on the adolescents' ability to cope with their experience. It is anticipated that the recommendations will help the adolescent cope with their experience.

Life Changes

Conquering the experience of cancer for these adolescents changed their lives. The notion of life changes appears often in literature on chronic illness (Kralik, 2002; Leaver, 2001; Bishop, 2001). The life changes experienced by these adolescents included, feeling different, reduced adolescent risk taking behaviour, self perception, and altered body image.

Feeling different

The adolescents in this study discussed their life changes in relation to how they felt different from their peers. The adolescents were not concerned that these changes had made them different from their peers, and often changed friends due to this difference. Enskar et al.'s (1997) study in which the adolescents had a changed outlook on their lives supports the CCE study. This is also supported by Claflin and Barbarin (1991), and Steefal's (2000) research into adolescent cancer survivors. These studies identified that adolescents who were diagnosed and treated for cancer felt older than their peers, possibly due to their coping with situations that they ordinarily would not have had to cope with at this stage in their development.

The feeling that their lives had changed, and their changed self perception, was a result of the coping strategy of positive reappraisal. Positive reappraisal is a coping strategy, which describes how the adolescent creates a positive meaning of their experience (Folkman, et al. 1986). The adolescents in this study described how their lives had been changed and that they felt more mature than their peers. They seemed to have developed a positive slant on their experience.

It is therefore recommended that education through workshops, inservices, or conference papers about these life changes be available to staff caring for adolescents with cancer. This education could provide strategies for staff to help the adolescent cope with their experience and to normalise their experience. Courses are available for

adolescents with chronic illness to assist them to reflect on their experience and how this has changed them. This helps them to cope and gain meaning from their experience. The development of a course similar to this is being developed through the “Seize the Day” group for adolescents with cancer, and it is recommended that adolescents be encouraged to attend this program.

Risk-taking behaviour

Risk-taking behaviour is described in many studies of ‘healthy’ adolescents and includes drug taking, sexual activity, and dangerous pursuits. The adolescents in the study group actively avoided risk-taking behaviour after they had completed their cancer treatment. This is a similar finding to Steefel (2000), Hollen and Hobbie (1996) and Enskar et al.’s (1997) studies. The adolescents found that they were different from their peers because they had experienced cancer and were now stronger for the experience. The implications of this are that adolescents may find that they are further isolated from their peers due to their different experiences.

Avoiding risk-taking behaviours is an example of adolescents using the coping strategy of self-control. The coping strategy of self-control describes the adolescents actively trying to gain control of themselves and their environment (Folkman, et al. 1986). Throughout their treatment the adolescents often felt out of control. The adolescents used the coping strategy of self control, to regain some control in their lives.

It is therefore recommended that staff and parents support adolescents with cancer in their decisions to avoid risk-taking behaviour. Helping the adolescents and their parents realise that it is not unusual for adolescents who have conquered cancer to avoid risk-taking behaviour would help them to cope with their experience. In addition, encouraging new social networks through support groups may enhance the adolescent’s social support.

Self perception

The self perception of the adolescents in this study seemed to be more mature than other adolescents their age. The differences in self perception may have been due to their experience with cancer, and may lead to them feeling different from their peers which may also cause the adolescent to have less social support. Steefal (2000) identified that adolescents who were diagnosed and treated for cancer felt older than their peers. In addition, Enskar et al.'s (1997) study also found that adolescents who had been treated for cancer felt more mature than their peers. Smith, Ostroff, Tan and Lesko (1991) undertook a study in the USA into the alterations of self perceptions among adolescent cancer survivors. They identified that the adolescents experience with cancer impacted on how the adolescent perceived themselves which correlates well with the CCE study. Additionally, Maggiolini et al.'s (2000) study into the self image of adolescent survivors of childhood leukaemia identified that the participants were more mature in their self concept than the control group.

It is recommended that nursing staff help the adolescent and their parents to deal with this difference and provide support if required. This support could be given through discussion and education of parents into the changes that may occur to their adolescent, and strategies to help their adolescent cope with their experience such as joining support groups, and attending programs designed to help them cope. Further research would provide a greater insight into how the experience of being treated for cancer affects an adolescent's self-perception.

In summary, the life changes that occur as a result of their diagnosis and treatment do have an impact on the adolescents with cancer. These changes have led the adolescents in this study to feel different, to not be involved in risk taking behaviours and to have a changed perception of themselves. The adolescent's cancer experience has led to these changes.

Limitations

The research methods used in this study were rigorously applied, however, there are several limitations. The data for this study was gathered via interviews of adolescents conducted before the commencement of this study. The questions used in these interviews may have limited the variability of data collected, and therefore limited the data used in the theory. There was also limited diversity in the cultural background of the adolescents. For example, no adolescents of indigenous background were included in the study, which places a distinct limitation on the applicability of the findings across a cultural context. Most of the adolescents whose interviews were used for this study had completed their treatment, which may have led to the positive outcomes of the theory. However, there were some adolescents who were still receiving treatment involved in the study. Further, as the study set out to identify the coping strategies of adolescents with cancer, transferability of the results to adolescents with other types of health problems may be limited.

Implications for practice

The results of this study indicate that adolescents with cancer use various strategies to cope with their experience, and the adolescents in this study had positive outcomes from their experience. The recommendations of this study are numerous and have been divided into three subsections, recommendations for health professionals, further research, and hospital planners. These recommendations aim to improve support for adolescents as they cope with their experience. Currently these recommendations for practice are not undertaken consistently in all hospitals across Queensland. The adolescents in this study were treated at various hospitals across Queensland, and therefore the recommendations are broadly applicable to any institution that provides treatment for adolescents with cancer.

Recommendations for health professionals

The recommendations for health professionals describe actions the hospital staff can implement to improve the adolescents' ability to cope with their situation. The adolescents wanted to be involved in decision making about their diagnosis, prognosis and treatment. It is recommended that adolescents with cancer be involved in decision making discussions with their consultant, however they also need the support of their parents. The adolescents should also be included in decision making about bed allocation when in hospital. Involving the adolescent in decision making would help to foster a trusting environment for the adolescent.

The adolescents in this study described how they used the support of their family and peers to help them cope with their experience. It is recommended that the staff encourage visits, phone calls or emails from their family and peers. Through encouraging the adolescent to access their family and peer supports it is anticipated that these supports will help the adolescent to better cope with their experience. It is also recommended that nursing staff encourage medical staff to allow the adolescent to travel home as often as possible taking into consideration their current or potential physical state during the time they will be away. It is anticipated that these recommendations will help the adolescent to cope with their experience.

Education of staff in the unit would also assist to positively change the care provided to adolescents with cancer. Within the oncology unit at the RCH, education of staff focuses on the technical aspects of cancer care including, giving chemotherapy, side effects of treatment, and types of cancer. There is limited education provided to nursing staff about the impact of undergoing treatment for an adolescent. The education provided to nursing staff is bench marked with other oncology units across Australia so it can be assumed that this is standard practice for oncology units in Queensland.

The education materials developed could be provided to staff through workshops, inservice or conference papers. The education should include the topics of, life changes, fatigue, communication and developing relationships with adolescents. It is recommended that nursing staff are educated about the life changes that occur to adolescents due to their treatment. It is anticipated that this education would help the nurses support adolescents as they experience life changes related to their treatment. It is also recommended that nursing staff are provided with education about the effects of fatigue on the adolescent undergoing treatment for cancer and strategies to help the adolescent cope with their fatigue. Fatigue had an impact on how the adolescents coped with their experience. Through staff acknowledging the adolescent's fatigue and offering strategies to help the adolescent overcome their fatigue it is anticipated the adolescents will cope better with their experience.

Education regarding communication techniques is also recommended including strategies for developing relationships. These strategies would help the staff to develop an honest and trusting relationships with the adolescent. Communication between both hospital staff, and adolescents and their family needs to be addressed. The adolescents in this study found that staff often did not talk to them or explain important aspects of their care to them. The staff would explain treatment or diagnosis with their parents and would not talk to the adolescent about this directly. Education on these topics is not generally provided to staff caring for adolescents with cancer and the resulting change in nursing practice would help the adolescent to cope with their experience.

Table 5.3 - Recommendations for health professionals

- | |
|---|
| <ul style="list-style-type: none">• Involvement in decision making about their care with the support of their parents.• The development of education resources for staff .• Encourage visits, phone call and emails with peers and family.• Allow the adolescent to travel home as frequently as possible. |
|---|

Through the implementation of these recommendations for health professionals (Table 5.3, page 112) it is anticipated that staff will improve their care and support given to adolescents with cancer. Through improving the care and support provided to adolescents with cancer it is anticipated that there will be an improvement in their ability to cope with their situation.

Recommendations for further research

The recommendations for further research (in Table 5.4) describe potential research projects into adolescents with cancer. Research into the implications of cancer on the adolescents developmental trajectory would provide a better understanding of what changes occur in the adolescents lives due to their diagnosis. Additionally a review of the meals provided to adolescents with cancer may identify areas that would improve the food provided to adolescents with cancer in hospital. It is important that this research has an adolescent focus as previous research has been conducted into adult nutritional issues. The thorough literature review conducted in this study revealed a few published research into these topics. It is anticipated that further knowledge in this area will help the adolescent with cancer cope with their experience more effectively.

Table 5.4 - Recommendations for further research

- | |
|---|
| <ul style="list-style-type: none"> • Implications of cancer on the adolescents developmental trajectory. • A review of the meals provided to adolescents with cancer. |
|---|

Recommendations for hospital planners

The recommendations for hospital planners are condensed into Table 5.5 and describe physical changes to the hospital environment that will improve the adolescents' ability to cope with their experience. These recommendations will help to improve the physical environment for the adolescents. The provision of somewhere to be active such as a half basketball court will help the adolescents to cope with boredom

and fatigue. Additionally the provision of equipment such as telephones, email will help the adolescent to keep in contact with their family and peers while they are hospitalised and assist support provided to adolescents with cancer by their peers and family. Also an area to prepare food that they want to eat will help to maintain the adolescents nutritional status and encourage a family environment by allowing the family to cook and eat meals together as they would have at home. It is also recommended that the adolescents family be allowed unrestricted access to the adolescent while they are in hospital as the family acts as support for the adolescent in hospital.

Table 5.5 – Recommendations for hospital planners

- The provision of an area or areas close to the ward where the adolescents can be physically active.
- Equipment to allow for phone calls, email and age-appropriate distraction tools.
- A kitchen with a stove and microwave oven for parents and family to be able to prepare nutritious and appetising meals to the adolescent's tastes.
- Family be given unrestricted access to the adolescent while they are in hospital.

The implementation of these recommendations will have an impact on the nursing care provided to the adolescents with cancer. The nurses will be able to encourage the adolescents to participate in activities to help with their fatigue or boredom. They will also be able to encourage the adolescents to keep in contact with their peers, and to utilise the distraction tools available to them. Additionally the support provided by the adolescents with cancer by their family, peers, and through the provision of food, may help the adolescent to better cope with their experience. It is anticipated that the publication and implementation of these results will result in improvements to the hospital environment that help adolescents with cancer to cope with their experience.

In summary, this chapter discussed the key findings of this study and provided recommendations for practice to help improve the adolescents' ability to cope with

their experience. The key discussion topics of this chapter were factors which influenced coping, hospital environment and life changes. These topics also highlighted how Folkman et al.'s (1986) coping strategies were applied by the adolescents with cancer. Recommendations for practice were made in response to what the adolescents said they required. In addition, the limitations for the study and implications for practice were discussed.

FINAL COMMENTS

The diagnosis of cancer in adolescence is a life-changing event, and the strategies used to cope with these changes vary between individuals. The findings of this study support recommendations for nursing care for adolescents with cancer, which will hopefully improve their experience. Through support from family and staff and their own personal resources, the adolescents in this study were able to gain strength and resilience from a difficult situation.

Appendix 1: RCH Ethics Approval

DEPARTMENT OF PAEDIATRICS & CHILD HEALTH

Professor Ian Jones (Acting Head of Department) 3840 8777
Professor Jennifer Batch 3636 3767
Professor John Pearn 3365 5323
Assoc Professor Geoff Cleghorn 3365 5329
Assoc Professor James Nixon 3365 5332
Dr Roy Kimble 3365 5315
Dr Michael Nissen 3365 5021
Dr Jane Peake 3365 5333



Queensland Health

Level 3, RCH Foundation Building
Royal Children's Hospital
Herston Qld 4029 Australia
Telephone (07) 3365 5338/3365 5479
Facsimile (07) 3365 5455

10 May 2001

Ms. Tracey Laycock,
Project Officer,
Banksia Unit,
Royal Children's Hospital,
HERSTON.

Dear Ms. Laycock,

**The needs of adolescents with cancer in Queensland
Dr. Liane Lockwood and Ms. Tracy Laycock**

Many thanks for your kind submission of the above project to the Ethics Committee. I note that you would intend to have personal interviews with adolescents to find out the future needs for those who have been diagnosed with various types of cancer.

Thank you very much indeed for including the Information Sheet and the Consent Form and the other details of the project.

I am very happy to give executive approval for the project at this stage; this will be potentially ratified (after consideration) at our forthcoming full Ethics Committee meeting. Such approval is distinct from executive approval given by Professor Alan Isles (after consideration) as the District Manager.

Warmest and best personal wishes,

A handwritten signature in blue ink, appearing to read "John Pearn", written over a horizontal line.

Professor John Pearn.
Chair,

Royal Children's Hospital and District Health Service Ethics Committee.

c.c. Ethics Committee files (Professor John Pearn).
Members of the Ethics Committee.
Professor Alan Isles, District Manager, Royal Children's Hospital & District.

DEPARTMENT OF PAEDIATRICS & CHILD HEALTH

Professor Ian Jones (Acting Head of Department) 3840 8777
Professor Jennifer Batch 3636 3767
Professor John Pearn 3365 5323
Assoc Professor Geoff Cleghorn 3365 5329
Assoc Professor James Nixon 3365 5332
Dr Roy Kimble 3365 5315
Dr Michael Nissen 3365 5021
Dr Jane Peake 3365 5333



Queensland Health

Level 3, RCH Foundation Building
Royal Children's Hospital
Herston Qld 4029 Australia
Telephone (07) 3365 5338/3365 5479
Facsimile (07) 3365 5455

28th May 2001.

Ms. Tracey Laycock,
Project Officer,
Banksia Unit,
Royal Children's Hospital,
HERSTON.

Dear Ms. Laycock,

Further to my earlier letter I am writing formally to say that the Ethics Committee of the Royal Children's Hospital & District Health Services has reviewed your submission; and that the Committee has approved the project.

The Ethics Committee here does require all researchers to have an intention to publish their research in a refereed journal. We would appreciate a copy of the final published work when this has been achieved.

The Committee joins with me in sending you all best wishes for this important study and we wish you success in its successful completion.

With kindest regards,

A handwritten signature in blue ink, appearing to read "John Pearn".

Professor J.H. Pearn.
Chair,

Royal Children's Hospital and District Health Service Ethics Committee.

c.c. Ethics Committee files (Professor John Pearn).
Members of the Ethics Committee.
Professor Alan Isles, District Manager, Royal Children's Hospital & District.

Appendix 2: ACU HREC Approval



AUSTRALIAN CATHOLIC UNIVERSITY
Human Research Ethics Committee
Approval Form

Principal Investigator/Supervisor:	Ms Paula Schulz/Dr Karen Mason	Campus: McAuley
Student Researcher:	Ms Tracy Laycock	Campus: McAuley

Ethics approval has been granted for the following project:

The health needs of Queensland adolescents with Cancer

for the period: 1 January 2002 to 30 June 2002

Human Research Ethics Committee Register Number: Q2001/02-7

subject to the following standard conditions as stipulated in the *National Statement on Ethical Conduct in Research Involving Humans* (1999):

- (i) that Principal Investigators / Supervisors provide, on the form supplied by the Human Research Ethics Committee, annual reports on matters such as:
 - security of records
 - compliance with approved consent procedures and documentation
 - compliance with special conditions, and
- (ii) that researchers report to the HREC immediately any matter that might affect the ethical acceptability of the protocol, such as:
 - proposed changes to the protocol
 - unforeseen circumstances or events
 - adverse effects on participants;

and subject to the following special conditions being met, as stipulated by the Human Research Ethics Committee:

- In the initial information letter (Appendix 1), 5th paragraph, the researcher has indicated that the participants may bring "other friends who have cancer" along to the interview. This possibility, however, is not mentioned anywhere else in the application. The Committee requests that, if it is the researcher's intention to conduct interviews at which more than one adolescent is present, she provide justification for this and indicate the procedures she will follow in obtaining all the appropriate consents. In this case, the "friend/s" will in effect become participants in the project.
- The Committee requests that the researcher not use the survey sheet (second page of Appendix 1). In line with this, the last paragraph of the initial information letter should be rewritten as an invitation for those interested in participating to approach the researcher—either in person, in writing, or by phone. Prospective participants who are under eighteen years of age should be asked to indicate this. All prospective participants will then be sent the formal Information Letter to Participants and the consent form. In the case of those under eighteen the Information Letter to Parents will be sent, together with the consent form.

- In the Parent/Guardian Consent Form, please insert a statement whereby the parent/guardian is invited to consent to counselling being provided should the adolescent request it.
- The Committee requests that, in order to ensure confidentiality, participants not be identified by the first letter of their names. Codes should be used that allow for full de-identification of the data.

Within one month of the conclusion of the project, researchers are required to complete a *Final Report Form* and submit it to the local Administrative Officer (Research and Ethics).

If the project continues for more than one year, researchers are required to complete an *Annual Progress Report Form* and submit it to the local Administrative Officer (Research and Ethics) within one month of the anniversary date of the ethics approval.

Signed:Mr W.Foster.....
(Chair, Expedited Review Panel, HREC)

Date:3/12/01.....

**TO BE COMPLETED BY THE PRINCIPAL INVESTIGATOR
OR BY THE SUPERVISOR AND STUDENT RESEARCHER**

The Principal Investigator, or the Supervisor and Student Researcher, are to sign, date and return this form to the local Administrative Officer (Research and Ethics). Evidence of compliance with any special conditions set by the HREC should be provided when the form is returned. Please note that data-collection must not commence until the stipulated special conditions have been met.

The date when I/we expect to commence contact with human participants or access their records is:

.....

I/We hereby declare that I/We am/are aware of the principles and requirements governing research involving human participants, as expressed in the Human Research Ethics Committee's *Guidelines*, and I/We agree to the standard and special conditions (if applicable) stated above.

Signed: Date:
[Principal Investigator or Supervisor]

Signed: Date:
[Student Researcher]

TO BE COMPLETED BY THE CHAIR OF THE EXPEDITED REVIEW PANEL

I confirm that the special conditions stipulated by the HREC in relation to the commencement of data-collection have been met and that the conditions to be adhered to in the course of the project have been acknowledged by the researcher/s.

Signed: Date:

(ref: Ethaprvl Panel 180501.doc)

Appendix 3: Interview Schedule for RCH project

Warm up Questions

How old are you now?

How old were you when you were diagnosed?

How old were you when you finished treatment?

Q1. I want to know what hospital was like?

- What are some of the good parts about being in hospital?
- What are some of the bad parts about being in hospital?
- What did they have for you to do in hospital?
- What did you do that made being in hospital easier?
- How would you change the hospital to make it better?
- What were the hospital staff like to talk to?
What made it hard to talk to the staff at the hospital?
- If you were to be a teacher and you taught doctors and nurses how to talk to people your age what be some of the things you would tell them to make them be able to talk to you better.
- If you could design a ward for adolescents with cancer what would you put in it.
(You can do anything here)

Q2. Can you remember when you were diagnosed?

- Can you remember what they told about what was going to happen?
- What about side effects of treatment
- Did you get enough information?
- What sort of information would have been useful?
- How should it be given (like video's, books, talking to you)?
- Who do you discuss your cancer and treatment with the most? Is there any one you would have rather discussed this with?
- Do you think you are kept fully informed about what was going on with your treatment?
- Who do you think should be making your treatment decisions, Who usually does make the decisions
- Who do you think would benefit from information about cancer other than you?

Q3. Has your family life changed since you were diagnosed?

- Has your relationship with your parents, brothers and sisters or grandparents changed since you were diagnosed with cancer?
- Do you have different responsibilities now?
- Do you think you are more independent from your parents now? Has this changed?
Did it change when you were diagnosed?

Q3. What do you want to do for a job?

- Has this changed since you were diagnosed?

Q4. What did you do about school while you were receiving treatment?

- How much school have you missed?
- Did you do school work while you were not at school?
- What about the hospital school? Did you find it useful
- How were your friends when you got back to school?

Q5 Have you been involved in any support groups?

Q6. Do you think anything positive has happened because you were diagnosed with cancer.

APPENDIX 4: SELECTED VERBATIM QUOTATIONS

The following quotations demonstrate how the categories represent the data.

CONDITIONS

SOCIAL SUPPORTS

Parents/family

Steve: "And another good point was they didn't really have visiting hours that was you know if the family wanted to they could basically stay there so you could be surrounded by a network of friends and family if you had that which I know some people did that was good yeah. Um well there not too much you can say."

Sally: "you've got maybe your parent there and I was lucky enough to have my parents there but some people didn't. And that would be bad."

Peers

Sally: "You know they were like oh you know I didn't want to talk to you because I didn't know what to say that also makes you feel worse because they don't want to talk to you so you think that there against you, you know what I mean. Then your like oh no one likes me or there going against me just because I have cancer and then you say well you know why don't you find out more about it or someone can tell you. Or maybe just like they are doing now having those cancer hot lines and things like that the only thing I don't really know if they would actually ring up. I don't think they'd actually do that. I don't really know how to do that."

Eliza: "Um they kind of tried to be support but they weren't um they were kind of like the cool group they sort of like um probably I didn't see them much when I was sick I kind of didn't agree with all the things they did. Oh ok I just sort of felt like I just had cancer and you guys all want to smoke or you just want to have drugs where I didn't have a choice about whether or not I had the drugs put into men in the hospital it just made me not have their point of view so. I stopped being friends with them."

Mark: "Um I think kids at school they like he's got cancer on that week I was in hospital they actually killed the main cancer and after know they're trying to just kill cause its lymphoma trying to kill all the little cancer they're like oh he's got cancer and stuff like that sometimes they're a bit touchy like don't bump him my friends are always being really careful I suppose I was weaker and stuff but I wasn't that weak that they couldn't bump me they were very careful they were protecting me so people wouldn't crash into me . and so the kids at school would benefit a lot."

Therapeutic relationships.

Mark: "Um well there always caring, always looking after you and stuff which you know something that sometimes you don't have that kind of service and stuff like that. There all really nice and caring and they try and help you through it the nurses and stuff like that I can't really think of anything else"

Steve: "Staffing wise for myself anyway 9D they were fantastic they sort of where beyond the call of duty really in caring they sort of took it to a personal level which is beneficial for the patients in lots of ways they can feel a bit more cared for than the usual duty like care that they expect to receive anyway."

Chris: "Oh don't talk down at it. Like to the kids they talk at em not too em and don't talk to there parents all the time. Talk to the people themselves."

Joshua: "Just be nice and I don't know ask them what their hobbies, catch up on their hobbies or something then you'd have something to talk to them about when their in hospital."

SITUATIONAL ISSUES

Distance from home

Frank: "Well were actually at Cooktown that's about nearly 900 kilometres or something."

Age of others in hospital

Eliza: "Well I went to the XYZ Hospital and it was an adult hospital. So it was probably it was probably not as good as it would have been in a children's hospital because especially in the oncology ward like I was pretty much surrounded by old dying people and yeah so it was probably an unpleasant experience it wasn't oriented towards children. So it was like quite plan and unfun and really really scary."

Mark: "Um well it could be a bit more sound proof I find the babies are a bit (whinge, whinge) all the time and that make it hard, babies are annoying but I can't really think."

Food

Eliza: "Yeah I'm probably the only person out there who actually likes hospital food."

Joshua: "You get sick can't stand hospital food."

Interviewer: "What do you do when the hospital food's really yuck?"

Joshua: "We don't let it in mum just takes it out. And I'm not sure I just get sick most of the time."

Joshua: "Cause I can smell the food when it not even coming. It just makes me feel sick."

Steve: "The food is dreadful that's one of the biggest points."

Mark: "Well we bring food in sometimes because I don't like hospital food unless its like some thing they can't grease up like the jelly that was alright last night I drinks that powder stuff they have."

Available resources

Joshua: "Yeah cause then like everyone takes the games like people take the games from when you in outpatients people take the games. They steal them so you can't play most of them. I reckon they should get some good games like a Sony and get like Jonah Lomou rugby or something."

Steve: "I thought it was pretty disgusting that people had to pay to watch public television. That was shocking. At the gold coast hospital we didn't have to pay at all."

CONTEXT

FEELING DIFFERENT

Being treated differently by friends

Sally: "I think friends and family because I know a lot of my friends when they found out the didn't know what to say to me. You know they were like oh you know I didn't want to talk to you because I didn't know what to say that also makes you feel worse because they don't want to talk to you so you think that there against you, you know what I mean. Then your like oh no one likes me or there going against me just because I have cancer and then you say well you know why don't you find out more about it or someone can tell you. Or maybe just like they are doing now having those cancer hot lines and things like that the only thing I don't really know if they would actually ring up. I don't think they'd actually do that. I don't really know how to do that."

Eliza: "Um they kind of tried to be support but the weren't um they were kind of like the cool group they sort of like um probably I didn't see them much when I was sick I kind of didn't agree with all the things they did. Oh ok I just sort of felt like I just had cancer and you guys all want to smoke or you just want to have drugs where I didn't have a choice about whether or not I had the drugs put into men in the hospital it just made me not have their point of view so. I stopped being friends with them."

When at home

Sally: "I think the worst bit was when your at home you feel more normal as far as normal can get. Um you've got friends around. You've got an actual bed with your possessions around you. You can eat and drink and move around however you want. Were as in hospital you can't because your connected to those um IV machines and what else. Just everything you can see your friends, just socialisation where as when your in there its just one room and you've got maybe your parent there and I was lucky enough to have my parents there but some people didn't. And that would be bad."

Frank: "Yeah they did. Yeah its really hard to explain there was suddenly less of everything like that. So yeah."

Being restricted

Chris: "One of the bad things were not being able to do something cause your so scared and stuff"

Interviewer: "Scared of what?"

Chris: "Like if you cut yourself and stuff knowing the consequences and that."

Mark: "I'm all sluggish and I always feel like lying down and I'm inside lying on the back couch and then they usually bring me food and stuff its before I'd be able and be normal I'd be walking around I'd probably be down at the basketball court or over at a friends house or something and wouldn't get home till six o'clock and now it like I'm home all the time and I can't go to a friends house I don't have the energy to go to the basketball court like throw a basketball."

LOSING CONTROL

Making decisions

Frank: "It was good because it gave me an active role in my treatment other than just receiving it. Um so yeah it was pretty good."

Eliza: "Um not really they sort spoke to my parents and not to me. They'd sort of speak like I wasn't there when I was sitting right there they didn't tell me what was going to happen they'd get my parents to decide and I would have rather that it was my decision?"

Feeling trapped

Sally: "I felt a bit sick it wasn't that bad the second time I went it I get my chemo then I stay till the next time I have to go in so I never even got to go home. I thought jeez I hope its not going to be like that next time it'll be better."

Steve: "Um well I don't know what else to describe hospital as I mean its in a way its worse than prison your not feeling well while your there and it can be quite lonely you know waiting on family and friends to visit is you learn to be you learn quite a bit of patience I don't know whether that's the reason where called patients yeah so."

Mark: "Oh just coming in because every time I come in I get some sort of you know, I thought I was just going be here overnight and now I've got a fever and I have to get my porta cath done and things like that always happen when you come in so I really frightened sort of full of nerves and jumpy around and that and just things like that things that are going to hurt and stuff that's sort of bad."

Feeling in the dark

Eliza: "Like my parents asked me what I thought but I thought the doctors should have asked me maybe consulted all of us not just mum and dad. I'm the one who has to live with it not my parents and not the doctors."

Joshua: "Nuh I got cause after this I've got two more chemo's till I'm finished and after that I asked the doctor and he said he doesn't worry about that till we get there so you don't know what's happening."

Steve: "I did keep up with everything. I didn't let anything happen but or get past me sorry. And um I think I did pretty well. I'm pretty up with all my treatment and what's happening."

Worrying

Eliza: "Not really I was still young so um yeah sort of just more worried about myself were as I used to like you know it used to be you know you sort of think about everyone in your family. But usually just think about yourself."

Steve: "You certainly get a lot of time to do a lot of thinking."

Feeling exhausted

Sally: "Well I slept most of the time. I was a sleeping person I think that's how I got over things. When I was awake I watched a lot of movies. My brain was very tired and I didn't want to do anything. So a lot of people had teachers coming through and the teacher would come through and say ok try this and at the beginning I did some then I just and then my brain didn't quite switch on."

PROCESSES

ESCAPING

Not thinking about it

Sally: "No I talked mostly about what would happen after. Not while I was there or what was happening."

Frank: "Mostly just pretended that I wasn't there. Just put it into my head that I wasn't there. That made it a lot easier."

Play

Eliza: "So and also I just got a game boy and I'd read magazines and that sort of thing. That sort of made it easier."

Joshua: "There nothing for the teenagers to do. There only the Sony but as I say they get taken by the other kids. So we've got nothing to do we just play cards."

Steve: "Um let me think. Actually the pay TV was quite good. That was really good. Watching video's and pay TV because you can't do very much at all, just very quiet things were non active, like just watching TV or thing like that or listening to music."

GAINING CONTROL

Keeping informed

Chris: "They told you at the start like gave you the like didn't just lay all the stuff in front of you like with all the pamphlets and stuff they gave you a little bit at a time not just one big handful cause. And that was good? It was good to give it to you slowly and in bits?"

Mark: "Um well I usually absorb most of my information when I'm talking to the nurses when they're doing things like putting the porta cath in after they've put the needle in I'll ask them questions and they'll give me an easy answer which I can understand in a book they might not be able I might not understand so I usually ask a couple of questions to nurses so like when I got this in I asked lots of question like its not going to be like this for a long time no just a few hours and you start to get used to it. So usually I get you know more direct information from the nurses."

Restructuring school program

Sally: "I repeated I didn't have to the teachers said it was ok and that they'd help me through it but I felt realistically and I would have loved to be with all my friends but I thought I could still be friends with them and then make new friends and I'd actually I won't be behind. Cause you know I don't want to go into life well I couldn't do this just because I had cancer. You know I may as well do something about it and repeat. So I could get good marks and know what I'm doing so I won't be stressed out saying oh no these people know all this and I don't know that yeah."

Joshua: "Three months, I still was able to do heaps with school work and stuff."

SEEKING NEW FRIENDS

Attending support groups

Sally: "Um I'm in Seize the day which is really good. Unfortunately I don't get to go to all the pizza nights they have every Friday oh not every Friday once a month on Friday."

Chris: "Just other people who have the same thing at the same age and stuff to talk to."

Socialising in hospital

Joshua: "They should sit all the people there own age like together so your not with a baby or that."

Joshua: "Yeah Its better having like your own age in there."

CONSEQUENCES

APPRECIATING LIFE

Being healthier

Sally: "I'm more motivated to be fit and healthy you know and eat healthy. I don't eat junk food. And I think that also preserves me to be a lot longer or about the same as an average person."

Sally: "At the moment you know a lot of teenagers taking drugs and you know going out and having sexual intercourse and things like that um and that I don't really do that cause I already I know what the effects are and what could happen and how dangerous it is and how short life could be if you don't take care of yourself I think I'm a lot more aware and a lot more cautious than a lot of other teenagers my age."

Feeling stronger

Eliza: "Um yeah it's made me a stronger person and I'm more able to stand up for my self now. Like um its made me appreciate life more so I live my life how I want I want to live it I sort of don't let anyone else tell me how to act or what to do."

Steve: "What doesn't kill you makes you stronger is certainly a very true statement and I've experienced that the hard way."

Mark: "Um I think it made me a stronger person and like um it opened up the wider like everyone so much went into chemotherapy so its opened up a great big chunk in my medical like an edge sort of thing I just what's the word work I didn't realise how much stuff there was and like how I suppose."

DEVELOPING NEW CAREER PATHWAYS

Chris: "Yeah I wanted to be a panel beater but not now."

Interviewer: "You don't want to do that now?"

Chris: "No"

Interviewer: "What made that change do you reckon?"

Chris: "Oh just all the fumes and stuff and the doctor said I couldn't so."

Steve: "I have a place at VBN-University for bachelor of environmental design urban and regional planning so town planning. Which is exactly that was my first choice. I got into that they were happy to have me I got good results. I was so rapt about that. Because I was diagnosed in January I was able to defer straight away cause I hadn't started and messed everything up which was fantastic."

Mark: "I did want to become a doctor but all the needles and stuff I'm not sure I feel like jabbing needles into people like I didn't realise they was so much if there was I want to become a doctor for the money and stuff I might become a radiographer that's easy you just look at the sheet."

REFERENCE LIST

- ABS. (2000). A statistical profile of Australia, Retrieved June, 20 2001, from the World Wide Web:
<http://www.abs.gov.au/austats/abs@.nsf/lookupresponses/08eb60bce5c60017ca25688d00098cc0?opendocument>
- ANCI. (2001). *ANCI code of ethics for nurses in Australia*. Canberra: ANCI.
- Baron, S. (2001). Boundaries in professional relationships. *Journal of American Psychiatric Nurses Association*, 7 (1), 32-34.
- Berger, A. (2003). Treating fatigue in cancer patients. *Oncologist*, 8, 10-14.
- Berger, P., & Luckman, T. (1979). *The social construction of reality a treatise in the society of knowledge*. Harmondsworth, London: Penguin.
- Berman, H., Harris, D., Enright, R., Gilpin, M., Cathers, T., & Bukovy, G. (1999). Sexuality and the adolescent with a physical disability: Understandings and misunderstandings. *Issues in Comprehensive Pediatric Nursing*, 22, 183-196.
- Birenbaum, L. K. (1990). Family coping with childhood cancer. *Hospice Journal*, 6, 17-53.
- Bishop, M. (2001). The recovery process and chronic illness and disability: Applications and implications. *Journal of Vocational Rehabilitation*, 16 (1), 47-52.
- Brook, C. (1993). *The practice of medicine in adolescence*. London: Edward Arnold.
- CanTEEN. (n.d.). *Tears of joy*. Sydney: CanTEEN.
- Carr-Gregg, M., & White, L. (1987). The adolescent with cancer: A psychosocial overview. *The Medical Journal of Australia*, 147, 496-502.
- Chambas, K. (1991). Sexual concerns of adolescents with cancer. *Journal of Pediatric Oncology Nursing*, 8 (4), 165-172.
- Chafetz, J. (1978). *A primer on the construction and testing of theories in sociology*. Itasca, Illinois: F.E. Peacock Publishers.
- Chandlers. (2004). Catalogue. Retrieved February 3, 2004, from the World Wide Web: <http://www.chandlers.com.au>
- Claflin, C., & Barbarin, O. (1991). Does "telling" less protect more? Relationships among age, information disclosure, and what children with cancer see and feel. *Journal of Pediatric Psychology*, 16, 169-191.
- CLCS (2004). What we do. Retrieved February 7, 2004, from the World Wide Web: http://www.clcs.org.au/what_we_do/default.asp

- Coyne, I. (1997). Sampling in qualitative research purposeful and theoretical sampling: Merging or clear boundaries? *Journal of Advanced Nursing*, 26, 623-630.
- Crotty, M. (1998). *The foundations of social research*. St Leonards, N.S.W.: Allen & Unwin.
- Curt, G., & Johnston, P.G. (2003). Cancer fatigue: The way forward. *Oncologist*, 8, 27-30.
- Davis, C., Girgis, A., Williams, P., & Beeney, L. (1998). Needs assessment of rural and remote women travelling to the city for breast cancer treatment. *Australian and New Zealand Journal of Public Health*, 22 (5), 525-527.
- Dunsmore, J., & Quine, S. (1995). Information, support, and decision-making needs and preferences of adolescents with cancer: Implications for health professionals. *Journal of Psychosocial Oncology*, 13 (4), 39-56.
- Dusseldorf Skills Forum. (1998). *Australia's youth: Reality and risk*. Sydney: Dusseldorf Skills Forum.
- Enskar, K., Carlsson, M., Golsater, M., & Hamrin, E. (1997). Symptom distress and life situation in adolescents with cancer. *Cancer Nursing*, 20 (1), 23-33.
- Fagerstrom, L., Eriksson, K., & Engberg, I. (1998). The patient's perceived caring needs as a message of suffering. *Journal of Advanced Nursing*, 28 (5), 978-987.
- Ferri, R., & Veroneau, P. (1998). Initiating dialogue with the adolescent patient. *American Nurse*, 30 (6), 6-7.
- Fletcher, H., & Bottomley, A. (2003). Fatigue and quality of life: Lessons from the real world. *Oncologist*, 8, 5-9.
- Folkman, S., Lazarus, R., Dunkel-Schetter, C., DeLongis, A., & Gruen, R. (1986). Dynamics of a stressful encounter: Cognitive appraisal, coping and encounter outcomes. *Journal of Personality and Social Psychology*, 50, 992-1003.
- Gauvin, M., Vandai, S., Mercier, P., & Bradet, R. (2002). Perception of the social support for adolescents who undergo corrective back surgery for scoliosis. *Issues in Comprehensive Pediatric Nursing*, 25, 207-216.
- Gibson, F., & Evans, M. (1999). *Paediatric oncology: Acute Nursing Care*. London: Whurr.
- Glaser, B. (1978). *Theoretical sensitivity : Advances in the methodology of grounded theory*. Mill Valley, California: Sociology Press.
- Glaser, B. & Strauss, A. (1967). *The discovery of grounded theory – Strategies for qualitative research*. New York: Aldine De Gruyter.

- Glasson, J. (1995). A descriptive and exploratory study into school re-entrance for adolescents who have received treatment for cancer. *Journal of Advanced Nursing*, 22, 753-758.
- Grbich, C. (1999). *Qualitative research in health*. Sydney: Allen & Unwin.
- Greenberg, H., Kazak, A., & Meadows, A. (1989). Psychologic functioning in 8- to 16-year-old cancer survivors and their parents. *Journal of Pediatrics*, 114 (3), 488-493.
- Griffin, J. (2003). *Immunology and Haematology* (2nd ed). London: Mosby.
- Griffith, K., & Hart, L. (2000). Characteristics of adolescent cancer survivors who pursue postsecondary education. *Cancer Nursing*, 23 (6), 468-476.
- Guenter, P., Ferguson, M., Thrush, K., & Coble Voss, A. (2002). Understanding tumour-induced weight loss. *MedSurg Nursing*, 11 (5), 215-228.
- Haddad, A. (2002). Ethics in action. RN, 65, 25. Retrieved May 15, 2003, from University of Queensland Library – Expanded Academic ASAP.
- Hampson, L. (2000). Adolescent health care: The Irish experience. *Paediatric Nursing*, 12 (3), 21-25.
- Hockenberry-Eaton, M., Hinds, P., Alcoser, P., O'Neill, J., Euell, K., Howard, V., Gattuso, J., & Taylor, J. (1998). Fatigue in children and adolescents with cancer. *Journal of Pediatric Oncology Nursing*, 15 (3), 172-182.
- Hodges, M., Graham-Pole, J., & Fong, M. (1984). Attitudes, knowledge, and behaviours of school peers of adolescent cancer patients. *Journal of Psychosocial Oncology*, 2 (2), 37-46.
- Hollen, P., & Hobbie, W. (1996). Decision making and risk behaviours of cancer-surviving adolescents and their peers. *Journal of Pediatric Oncology Nursing*, 13 (3), 121-134.
- Hooker, L. (1997). Information needs of teenagers with cancer: Developing a tool to explore the perceptions of patients and professionals. *Journal of Cancer Nursing*, 1 (4), 160-168.
- Hutton, A. (2002). The private adolescent: Privacy needs of adolescents in hospital. *International Pediatric Nursing*, 17 (1), 67-72.
- Hutton, A. (2003). Adolescents discuss sharing space in an adolescent ward. *Neonatal, Paediatric and Child Health Nursing*, 6 (2), 24-29.
- Keats, M., Courneya, K., Danielson, S., & Whitsett, S. (1999). Leisure-time physical activity and psychosocial well-being in adolescents after cancer diagnosis. *Journal of Pediatric Oncology Nursing*, 16 (4), 180-188.

- Kools, S., McCarthy, M., Durham, R., & Robrecht, L. (1996). Dimensional Analysis: Broadening the conception of grounded theory. *Qualitative Health Research*, 6 (3), 312-330.
- Kralik, D. (2002). The quest for ordinariness: transition experienced by midlife women living with chronic illness. *Journal of Advanced Nursing*, 39 (2), 146-154.
- Kyngas, H., Mikkonen, R., Nousiainen, E., Ryttilähti, M., Seppanen, P., Vaattovaara, R., & Jamsa, T. (2001). Coping with the onset of cancer: Coping strategies and resources of young people with cancer. *European Journal of Cancer Care*, 10, 6-11.
- Lambert, V., Lambert, C., & Gugino, H. (1997). Crisis and Stress. In L. O. Burrell, M.J. M. Gerlarch, & B. S. Pless (Eds.), *Adult nursing acute and community care* (pp.74-82). Stamford, Connecticut: Appleton & Lange.
- Lazarus, R., & Launier, R. (1978). Stress-related transactions between person and environment. In Pervin, L., & Lewis, M. (Eds.), *Perspectives in Interactional Psychology* (pp. 287-327). New York: Plenum Press.
- Lewis, I. (1996). Cancer in adolescence. *British Medical Bulletin*, 52 (4), 887-897.
- Ljungman, G., McGrath, P., Cooper, E., Widger, K., Ceccolini, J., Fernandez, C., Frager, G., & Wilkins, K. (2003). Psychosocial needs of families with a child with cancer. *Journal of Pediatric Hematology/Oncology*, 25 (3), 223-231.
- Locke, K. (1996). Rewriting the discovery of grounded theory after 25 years. *Journal of Management Inquiry*, 5, 239-245.
- Lubkin, I., & Larsen, P. (2002). *Chronic illness: Impact and interventions* (3rd ed.). Sudbury, Massachusetts: Jones and Bartlett Publishers.
- Maggiolini, A., Grassi, R., Adamoli, L., Corbetta, A., Charmet, G.P., Provantini, K., Fraschini, D., Jankovic, M., Lia, R., Spinetta, J., & Masera, G. (2000). Self-image of adolescent survivors of long-term childhood leukemia. *Journal of Pediatric Haematology/Oncology*, 22 (5), 417-421.
- Mazurek, B., & Alpert-Gillis, L. (1998). The COPE Program: A strategy to improve outcomes of critically ill young children and their parents. *Pediatric Nursing*, 24 (6), 521-535.
- McCallum, L., & Carr-Gregg, M. (1987). Adolescents with cancer. *The Australian Nurses Journal*, 16 (7), 39-42.
- McDonald, J.T. (2001). Helping adolescents cope with cancer. *Journal of Pediatric Oncology Nursing*, 18 (3), 138-139.
- McGrath, P. (2002). Reflections on nutritional issues associated with cancer therapy. *Cancer Practice*, 10 (2), 94-101.

- McGrath, P., & Segueria, J. (2000). The patient transit assistance scheme: A consumer's perspective. *Australian Journal of Rural Health*, 8, 232-238.
- Miller, N., Freidman, S., & Coupey, S. (1998). Adolescent preferences for rooming during hospitalization. *Journal of Adolescent Health*, 23, 89-93.
- Minichiello, V., Aroni, R., Timewell, E., & Alexander, L. (1995). *In-depth interviewing: Principles, techniques, analysis*. Melbourne: Longman Australia.
- Morgan, S. (2003). NHS health and social care awards, Retrieved May 30, 2003, from the World Wide Web:
http://www.teenorg./z/pages/staff/care_awards.html
- Mulligan, K., & Bloch, A. (1998). Energy expenditure and protein metabolism in human immunodeficiency virus infection and cancer cachexia. *Seminars in Oncology*, 25 (2 suppl 6), 82-91.
- Neinstein, L. (1996). *Adolescent health care: A practical guide* (3rd ed.). Baltimore: Williams and Wilkins.
- Nelson, R., Botkin, J., Levetown, M., Moseley, K., Truman, J., & Wilfond, B. (1999). Appropriate boundaries in the pediatrician-family-patient relationship. *Pediatrics*, 104 (2), 334-336.
- Perrin, E., & Gerrity, P. (1984). Development of children with a chronic illness. *Pediatric Clinics of North America*, 31 (1), 19-31.
- Pinkerton, R., Michalski, A., & Veys, P. (1999). *Clinical challenges in paediatric oncology*. Oxford: Isis Medical Media.
- Pinkerton, R., Plowman, P., & Pieters, R. (2004). *Paediatric Oncology*. London: Arnold.
- Pizzo, P., & Poplack, D. (2002). *Principles and practice of pediatric oncology*. Philadelphia: Lippincott Williams & Wilkins.
- Polit, D., & Hungler, B. (1999). *Nursing research: Principles and methods* (6th ed.). Philadelphia: Lippincott.
- QLD Cancer Fund. (2004). Cancer info and services. Retrieved February 7, 2004, from the World Wide Web:
<http://www.qldcancerfund.com.au>
- QNC. (1999). Guidelines for Registered nurses and Enrolled Nurses: Regarding boundaries and professional practice. Brisbane: QNC.
- Queensland Cancer Registry. (2000). *Cancer in Queensland: Incidence and Mortality 1982-1998*. Brisbane, Queensland Health, Retrieved March, 21 2001, from the World Wide Web:
<http://www.health.qld.gov.au/hic/1998cancer.pdf>

- Riley, V. (1998). Dangerous liaison. *Nursing Times*, 11 (94), 30-31.
- Ritchie, M.A. (2001a). Psychosocial nursing care for adolescents with cancer. *Issues in Comprehensive Pediatric Nursing*, 24, 165-175.
- Ritchie, M.A. (2001b). Self-esteem and hopefulness in adolescents with cancer. *Journal of Pediatric Nursing*, 16 (1), 35-42.
- Ritchie, M.A. (2001c). Sources of emotional support for adolescents with cancer. *Journal of Pediatric Oncology Nursing*, 18 (3), 105-110.
- Roberts, C., Turney, M., & Knowles, A. (1998). Psychosocial issues of adolescents with cancer. *Social Work in Health Care*, 27 (4), 3-18.
- Rudin, M., Martinson, I., & Gilliss, C. (1988). Measurement of psychosocial concerns of adolescents with cancer. *Cancer Nursing*, 11 (3), 144-149.
- Rynard, D., Chambers, A., Klinck, A., & Gray, J. (1998). Social support programs for chronically ill children: Evaluating the adjustment of children with cancer at school. *Children's Health Care*, 27 (1), 31-46.
- Santrock, J.W. (2001). *Child Development* (9th ed.). Boston: McGraw Hill.
- Santrock, J. W. (2004). *Life-span development* (9th ed.). New York: McGraw- Hill.
- Schneider, S., & Workman, M. (2000). Virtual reality as a distraction intervention for older children receiving chemotherapy. *Pediatric Nursing*, 26, 593-602.
Retrieved June 26, 2003, from University of Queensland Library – Expanded Academic ASAP.
- Schatzman, L. (1991). Dimensional analysis: Notes on an alternative approach to the grounding of theory in qualitative research. In Maine, D. (Ed.), *Social organisation and social process: Essay's in honour of Anselm Strauss* (pp. 303-314). New York: Aldine De Gruyter.
- Seifert, K. & Hoffnung, R. (2000). *Child and adolescent development* (5th ed.). Boston: Houghton Mifflin.
- SERG. (n.d.). Guidelines for research on reproductive health involving adolescents. Retrieved January 18, 2003 from the World Wide Web:
<http://www.who.int/reproductive-health/nrp/guidelines.en.html>
- Smith, K., Ostroff, J., Tan, C., & Lesko, L. (1991). Alterations in self perceptions among adolescent cancer survivors. *Cancer Investigation*, 9 (5), 581-588.
- Spinetta, J., Masera, G., Jankovic, M., Oppenheim, D., Martins, A., Arush, M., van Dongen-Melman, J., Epelman, C., Medic, G., Pekkanen, K., & Eden, T. (2003). Valid informed consent and participative decision-making in children with cancer and their parents: A report of the SIOP working committee on

- psychosocial issues in pediatric oncology. *Medical Pediatric Oncology*, 40, 244-246.
- Steefel, L. (2000). Adolescent cancer survivors. *Nursing Spectrum (My New Jersey Metro edition)*, 12A (24), 6-7.
- Stern, P. (1994). Eroding grounded theory. In Morse, J. (Ed.), *Critical issues in qualitative research methods* (pp. 212-223). London: Sage.
- Stern, M., Norman, S., & Zevon, M. (1993). Adolescents with cancer, self-image and perceived social support as indexes of adaptation. *Journal of Adolescent Research*, 8 (1), 123-142.
- Stewart, M., Ellerton, M., Hart, G., Hirth, A., Mann, K., Meagher-Stewart, D., Ritchie, J., & Tomblin-Murphy, G. (1997). Insights from nursing research program on social support. *Canadian Journal of Nursing Research*, 29 (3), 93-110.
- Strauss A. (1987). *Qualitative analysis for social scientists*. Cambridge: Cambridge University Press.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and Procedures for developing grounded theory*. Thousand Oaks: Sage Publications.
- Strauss, A., & Corbin, J. (1994). Grounded theory methodology: An overview. In Denzin, N. & Lincoln, Y. (Eds.), *Handbook of qualitative research* (pp. 273-285). London: Sage.
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park: Sage Publications.
- Virtual Realities. (2004). Retrieved February 3, 2004, from the World Wide Web: <http://www.vrealities.com>
- Weiner, M. A., & Cairo, M.S. (2002). *Pediatric hematology/oncology secrets*. Philadelphia: Hanley & Belfus, Inc.
- Whelan, J. (2003). Where should teenagers with cancer be treated? *European Journal of Cancer*, 39, 2573-2578.
- Whyte, F., & Smith, L. (1997). A literature review of adolescence and cancer. *European Journal of Cancer Care*, 6, 137-146.
- Wilson, M. (2001). Crossing the border: Separating professional concern from personal attachment. *American Journal of Nursing*, 101 (4), 24.
- Wimpenny, P., & Gass, J. (2000). Interviewing in phenomenology and grounded theory: is there a difference? *Journal of Advanced Nursing*, 31, 1485-1492.
- Winningham, M., Nail, L., Barton Burke, M., Brophy, L., Cimproch, B., Jones, L., Pickard-Holley, S., Rhodes, V., St. Pierre, B., Beck, S., Glass, E., Mock, V.,

- Mooney, K., & Piper, B. (1994). Fatigue and the cancer experience: The state of the knowledge. *Oncology Nurses Forum*, 21, 23-36.
- Woodgate, R. (1998). Health professionals caring for chronically ill adolescents: Adolescents' perspectives. *Journal of the Society of Pediatric Nurses*, 3 (2), 57-68.
- Yalom, I. (1995). *The theory and practice of group psychotherapy* (4th ed.). New York: Basic Books.

Personal Communications

- J. Kanakis & B. Hartigan, personal communication, August 11, 2001. Co-ordinators for Leukaemia Foundation in Townsville and Brisbane.
- L. Keen, personal communication, August 7, 2001. Co-ordinator for 'Seize the Day' at the Cancer Fund.
- L. Kennedy, personal communication, September 23, 2004. Clinical Research Associate, Royal Children's Hospital, Brisbane, QLD.
- R. Lucas, personal communication February 7, 2004. Manager of Dick Smith – Toombul Shoppingtown, Brisbane QLD.