

1. Introduction

Childhood and adolescent cancer has evolved from being an inevitably fatal disease to a life-threatening chronic disease thanks to the introduction of modern treatment methods and therapies. Many more children and adolescents are furthermore surviving their disease than prior to the 1980's. Because of this it is important for the child or adolescent with cancer to be prepared to lead a full and active life after treatment has been completed (Bessel, 2001).

A literature survey has confirmed that the growing number of cancer survivors are experiencing both physical as well as psychological (including Post Traumatic Stress Disorder) and social adaptation difficulties following their cancer treatment (Ballenger, 2001; DeJager, 1996; Mackie, Hill, Kodrun & McNally, 2000; Stevens, Mahler & Parkes, 1998; Stuber et al, 1997).

Harding (2000) states that short-term effects such as alopecia and weight loss, which often accompany cancer treatment, are still perceived as being a stigma in certain sectors of the population. Peer groups often reject patients because of this stigma. The added problem of confusion between the physical manifestation of AIDS and cancer among lay people has also been seen as a drawback. Long term effects such as skeletal abnormalities, unsightly scars or subtle cognitive difficulties in certain cancer survivors have furthermore been viewed as being a concern.

Harding (2000) stresses the importance of an appropriately supportive family and staff (working within a multi-disciplinary team approach) when it comes to successful psychosocial adaptation both during and following the active treatment phase. Many other authors share this view and some intervention programs have been developed in order to facilitate psychosocial adjustment both during and after treatment (Newby, Brown, Pawletko, Gold & Whitt, 2000; Wright, Selby, Gould & Cull, 2001).

2. Aim

The aim of this mini dissertation is to review the international literature pertaining to psychosocial adaptation during and following the diagnosis and treatment of childhood and adolescent cancer.

Aspects, which will receive attention in this review, are the role of psychoneuroimmunology and the biopsychosocial approach to investigation and research in psychological research, psychosocial adaptation of childhood and adolescent cancer survivors as well as Quality of Life issues pertaining to the development of psychosocial intervention programs in cancer care.

Special attention will be given to literature pertaining to trauma spectrum symptoms and traumatic stress sequela with specific reference to patients with childhood and adolescent cancer such as Osteosarcomas and Ewing sarcomas (hereafter Bone Sarcomas). Meaning making in relation to trauma will also be referred to briefly. Literature examining the role resilience plays in the psychosocial adaptation of adolescent cancer patient as well as the need for a resilience centred approach in research will also be explored.

3. The role of Psychoneuroimmunology and the Biopsychosocial approach to investigation and research in psychosocial adaptation following the diagnosis of cancer

Psychology has tended to draw almost exclusively upon scientific methods of study to pursue its research questions thus following the Biomedical Model of research almost exclusively (Rogers, 1996). It was only when the link between the brain and the immune system in rats was 'proven' in a scientific trial (run according to the biomedical model) by Robert Ader, that Psychoneuroimmunology was 'born'. Ader saw the vast potential in his early 1970s research. He believed that, if immune responses could be modified through environmental and

psychological stimulation, the potential for activating the immune system against disease, especially cancer, was enormous.

Although the exact nature of the interplay between the psychological and physiological mechanisms which influence wellness in the human being needs to be examined in more depth, there is enough evidence to support the use and efficacy of psychosocial therapy in cancer care (Fox, Timothy, McCain & McCain, 1999).

The USA government is funding hundreds of trials in PNI research. Ader finds this trend both gratifying and frightening. He states that the basic research is not a "fad", but fears that the way the term is being bandied about in lay literature, is fast leading to PNI becoming one. He advocates caution when claims that every type of psychosocial therapy and relaxation technique can boost the immune system are made (Azar, 1999).

That many of these techniques have beneficial effects upon the Quality of Life and even prognosis in certain cancer patients cannot however be disputed (Caudell, 1996; DuBose, 1995; Schlebusch, 1999). It is important though to understand the complexity of the relationships between cognitive images of the mind and the central nervous system and consequently endocrine and immune systems before implementing any such programs (Anderson, 2001).

Most importantly the person needs to be viewed as consisting not only of body, but body, soul (including mind) and spirit. All these aspects as well as the fact that each person is an integral part of a family as well as social system needs to be considered when research in this area is planned and executed. The developmental phase of both patient and family as well as the age of the patient needs to be taken into account. Ethical considerations make this a difficult area to study using the biomedical model and alternative, more qualitative research methods can be positively employed in this field.

Intervention programs need to be structured in such a way that the 'personhood' of the individual with cancer is not crushed. The importance of family and social support cannot be stressed enough and the effective use of the multidisciplinary approach is crucial. Another aspect, which enhances well being, is the empowerment of the patient and family through appropriate psycho education and information provision (McLoughlin, 1994).

It is only recently that psychology has started using the biopsychosocial model for research and qualitative studies are only now being recognized in the field (Chesler, 1993; Marks, 1996; National Cancer Institute, nd.; Rogers, 1996; Ryff & Singer, 2000; Veach & Nicholas, 1998).

With the above in mind literature pertaining to Quality of Life, the importance of appropriate support programs and psychosocial adaptation of the child and adolescent cancer patient will be discussed.

4. Quality of Life (QoL) and the development of psychosocial support programs



The promotion of quality of life in the treatment of cancer has become an integral part of Oncology Units worldwide. This is no different in South Africa and the development of intervention programs which can enhance quality of life in the psychosocial sphere are imperative (Ades, Gansler & Eyre, 2001; Bland, 1997; Bonn, 1999; Fallowfield, 1995; Fallowfield, 1996; Garsenna & Goodkind, 1999; Greer, 1999; Gudas, & Burns, 1998; Hollen, 1999; Hollen, Hobbie & Finley, 2000; Riba, 2002; Slimack, Tomori & Bennett, 2000; Spiegel, 1995).

In recent literature pertaining to cancer in children and adolescents the importance of information provision and psycho education as tools for coping with the disease and in so doing improving quality of life has been highlighted (Ades, et al, 2001; Broersa, Kapteina, Le Cessieb, Fibbec,

& Hengeveld, 2000; Butow, Kazemi, Beeney, Griffin, Dunn & Tattersall, 1996; Connerly, 2001; Ettinger & Heiney, 1993; Fallowfield, Hall, Maguire, Baum & A'Hern, 1994; Fallowfield, 2001; Fleissig, et al, 2000; Kazak, et. al, 1999; Kyngas, Mikkonen, Nousiainen, Ryttilahti, Seppanen, Vaattovaara & Jamsa, 2001; Leydon et al., 2000; Leydon, Boulton, Moynihan, Jones, Mossman, Boudioni & McPherson, 2000; McLoughlin, 1994; Meridith, et al. 1996; Payne, 2000; Pimental, Ferreira, Real, Mesquita, & Maia-Goncalves, 1999; Soothill, Morris, Harman, Francis, Thomas, & McIlmurray, 2001).

The aspect of Quality of Life improvement is an integral component in the development of any individualized program for cancer patients of all ages as individualized psycho education forms a large part of such intervention programs.

Being able to cope with the diagnosis and treatment of cancer has also been linked to many other factors including family system, resilience and social support (Sawyer, Antoniou, Toogood & Rice, 1997).

Culling (1988); Kupst, (1993); Kyngas, et al. (2001), and Rowland (1989) stress that the individual and family's pre-existing coping strategies play a major role in how they will react to the crisis of cancer. By offering early intervention, it should be possible to prevent maladaptive coping styles from becoming entrenched (Thomas, Glynne-Jones, Chait & Marks, 1997).

The child/adolescent displays a number of coping techniques, which should allow him to come to terms with the illness and to lead a rewarding life, maintaining emotional growth and social support. The patient's first task is to accept the limitations imposed by the disease and to accept some responsibility in the management of the illness as well as to comply with procedures.

Secondly the patient needs to be taught skills in how to manage anger and frustration. Some people may develop compensatory physical or intellectual skills to balance the loss imposed by the illness. They may also utilise defence mechanisms such as denial and suppression in order to keep anxiety manageable (Bradwell & Hawkins, 2000; Culling, 1988; Kyngas, et al., 2001).

Yeh, Lee, Chen and Li (2000) conducted a study, which looked at how parents in Taiwan adapt to their children's cancer. It was found that they adapt by a dynamic process: they modify their coping tasks and related strategies as events such as diagnosis, side effects or death occur. Five components were identified within this adaptational process: confronting treatment, maintaining family integrity, establishing support, maintaining emotional well-being, and searching for spiritual meaning.

Culling (1988) stresses the importance of open communication and teamwork. The family, the patient and the members of the multidisciplinary team are all integral members of the team. The team counsellor's task is described as having the following components:

- To acknowledge and anticipate on behalf of the family the reactions and feelings they are likely to experience.
- To facilitate open communication between family members and to encourage expression of feelings.
- To educate the parents about possible difficulties the child might encounter regarding treatment.
- To educate parents about how to respond to questions and reactions of siblings and the patients.
- To recognise and acknowledge the family's positive qualities and their abilities to cope.
- Liaison between family and hospital staff and other agencies involved.

The support function of group interaction is furthermore stressed by Culling (1988), as well as Bradwell and Hawkins (2000). This form of intervention can be beneficial for both the patient and the family.

The above strategies were confirmed and stressed by numerous specialists in the field of child and adolescent cancer treatment: Prof. B. G. P. Lindeque, Dr Martin Chasen - Medical

Oncologist; Dr Norman Jaffe (personal communication, June 2002) and other international oncologists as well as by Bence (A. Bence, personal interview; March 20, 2001) during an interview at Johannesburg General Hospital's Paediatric Oncology Section. (Alta Bence is a social worker who has been working with paediatric cancer patients for more than 10 years.)

Any proposed program should be aimed at and focus upon creating the environment in which the above can take place.

Stam, Grootenhuis and Last, (2001) state that coping with the consequences of a life threatening disease can be regarded as a mediating factor in the adaptation of the survivor to the cancer experience. Few studies however have been done on the adaptation of survivors. These writers point out that many studies have been done on parental coping strategies, but few look at coping in relation to adjustment in survivors of childhood and adolescent cancer.

Boman and Bodegard (2000) refer to a previous study (Boman & Bodegard, 1995) in which long-term coping was assessed. It was concluded that many factors influence coping with the trauma of the illness experience. The severity of the disease and treatment seem to play a major role in long-term coping. Psychological profile and familial as well as social factors were not included in this study. Boman and Bodegard (2000) do however stress that these factors should be addressed in future research.

Noll, Gartstein, Vanetta, Correll, Bukowski and Davies (1999) hypothesised that children with cancer would have more social problems and difficulties with emotional well being including anxiety, than other children of the same age without the disease. The results of this study however indicate that the children with cancer do not demonstrate a statistically significant difference in either social problems or emotional well being than their classmates.

Although limitations to the study are acknowledged, various possible reasons for this are posited. All the children with cancer were being treated in a unit where support from staff

toward patients and families was well planned and co-ordinated. This context of support is seen as a contributing factor toward positive emotional well being and social adjustment. It is also postulated that the experiences with cancer and its treatment as well as facing the possibility of death may lead to the child being more empathetic toward others and thus not focussing upon own anxiety to such a great extent. Noll et al., (1999) encourages further research, which attempts to understand the mechanisms promoting the positive adaptation in children with cancer. The role of psychosocial services should also be researched according to these authors.

5. Psychosocial adaptation of cancer survivors

Mackie et al. (2000) state that the variability as well as deficits in research design concerning the study of adult psychosocial functioning following childhood or adolescent cancer has led to conflicting results in this field. Mackie et al., (2000) assessed 102 survivors of ALL (Acute Lymphoblastic Leukaemia) and Wilms' Tumour and 102 unrelated healthy peers. These participants were between the ages of 19-30 years. Standard adult psychiatric disorder, interpersonal and social-role performance as well as intellectual ability tests were used. No increased rate of psychiatric disorders was exhibited in the cancer survivor group. Poorer functioning was however reported in the areas of love/sex relationships, friendships, non-specific social contacts and day-today coping. These authors conclude that ALL and Wilms' tumour may have longterm effects on interpersonal functioning and coping. Different mechanisms such as lower intellectual ability may have an impact on the deficits illustrated. The need for prospective studies with each of these groups is stressed.

Stam et al. (2001) agree that many studies are deficient in method and sample size. They however present a comprehensive review of literature pertaining to the implications for emotional and social functioning which cancer treatment has upon the survivor. Studies published in English since 1985 were reviewed. Because the review is concerned with the functioning of survivors, parent and family functioning is only reported in connection with the survivors' functioning. Physical, neuropsychological or intellectual functioning are not reported. Studies where the survivors were

younger than 18 at the time of the study are included and all types of cancer are included as well. The criteria of a 5-year disease free period would have resulted in too few studies being eligible for inclusion in the review. It was decided to use the inclusion criteria of 20 or more survivors in the study coupled with the use of standardised measuring instruments. It is important to note that all the studies were conducted on groups with either mixed diagnoses, haematological cancers or brain tumours. Not one of the 52 studies reported results for Bone Sarcoma Patients only.

Because of the comprehensive nature of the review as well as the relevance of all the articles discussed in the review to the present study, the Stam et al., (2001) article can be viewed as being representative of the trends in research concerning psychosocial adaptation of child and adolescent cancer survivors.

This review covers the following aspects pertaining to social and emotional adjustment in the survivors of childhood cancer: Emotional adjustment, socio-behavioural adjustment and the predictive factors related to survivor's adjustment in the long term. Conclusions are drawn and recommendations for further study done.

The results of the review can be summarised as follows:

5.1 Emotional adjustment

Emotional adjustment was measured using many different instruments and in most cases the survivors were compared to a group of healthy peers or normative data. Overall

emotional functioning, self-esteem, anxiety and depression as well as PTSD symptoms were measured.

Most researchers found that psychological functioning in the cancer survivor group did not differ significantly from the norm or from their peers. Lesko in Stam et al. (2001) reported more global psychological distress in survivors than their peers, but pathological levels were not reached.

5.1.1 Self-esteem

Various authors used the Piers-Harris Children's Self-concept Scale. The results were conflicting in these studies. Anholt et al. and Olson et al. in Stam et al. (2001) found no difference in global self-concept between the survivors and their peers and the scores were within the norm. Furthermore cancer survivors in these studies felt better about their intellectual and school status, behaviour and overall happiness and satisfaction than their peers. Greenberg et al. in Stam et al. (2001) however reported poorer self-concept in survivors than in the peer control group. The scores of the survivors were however still within the norm. Fritz et al. in Stam et al. (2001) found better self-image in survivors than in the normative sample.

The Self-Perception Profile for Children was used by Radcliffe et al., Spirito et al. and Van Dongen-Melman to evaluate self worth (In Stam et al., 2001). No differences in general self worth were reported, but Radcliffe et al. in Stam et al. (2001) found that brain tumour survivors had less athletic competency resulting in lower self esteem. Van Dongen-Melman reported less athletic competency, but higher scores in physical appearance (In Stam et al, 2001).

Kazak et al., Madan-Swain et al. and Sloper et al. used the Self-Perception Profile for Adolescents (In Stam et al., 2001). None of these authors found any differences in global self worth in survivors compared to controls or normative samples. Bauld did not report any difference when using the Possible Selves inventory.

Von Essen et al. and Arvidson in Stam et al. (2001) used a standard self-report scale for Swedish children, the "I think I am" scale and report conflicting results. Von Essen et al. reports

lower self-esteem and lower scores on the psychological well-being and self-esteem subscales in survivors than in other children, while Arvidson found no difference (In Stam et al., 2001).

When body image is measured more conflicting studies are reported. Pendley et al. and Madan-Swain et al. in Stam et al. (2001) report poorer body comfort in survivors, while Pendley et al. could not confirm that study subjects had poorer body image in general than controls.

5.1.2 Anxiety and depression

Anxiety was measured using the Revised Children's Manifest Anxiety Scale (RCMAS) and the State-Trait Anxiety Inventory (STAI). Barakat et al., Sloper et al, and Von Essen et al. report no differences between the survivors and the control groups, while Bauld et al. and Kazak et al. reported higher state anxiety levels in survivors than in their peers (In Stam et al., 2001).

Kazak et al. and Radcliffe et al. in Stam et al. (2001) reported that survivors were less anxious than the normative values reported, but in another study Kazak et al. said this was true for males only.



Depression was measured by self-reports of survivors. Using the Children's Depression Rating Scale, Fritz et al. in Stam et al. (2001) found that the percentage of survivors who were depressed was no higher than in the general population. According to Stam et al. (2001) Van Dongen-Melman reported no difference using the Children's Depression Scale. Greenberg et al. and Von Essen et al. in Stam et al. (2001) using the Children's Depression Inventory also found no differences. Radcliffe et al. on the other hand found that brain tumour survivors were less depressed than their normative peers and Kazak et al. reported that feelings of hopelessness about the future were below the norm (In Stam et al., 2001).

5.1.3 Posttraumatic stress

(This aspect will be discussed in depth later in this mini dissertation.) In Stam et al. (2001) it would seem that although the incidence of PTS symptoms is no higher in survivors than others affected by stress, Pelcovitz et al. found that 35 % of adolescent cancer subjects met the criteria for lifetime PTSD compared to 7% of abused adolescents and 4% in the control group.

5.2. Socio-behavioural adjustment

Behavioural reactions, school-related problems, social competence and identity are categorised as socio-behavioural concerns. The Child Behaviour Checklist (CBCL), consisting of the Parent Report Form, The Teacher Report Form (TRF) and the Youth Self Report (YSR) are most widely used (In Stam et al., 2001).

Sawyer et al. in Stam et al. (2001) used the CBCL in two longitudinal studies and found that although more behavioural problems and less social competence was reported in the survivor group initially, the differences diminished with time and the survivors were on a par with their peers a few years after treatment was ceased.



The CBCL was also used in many longitudinal studies where the parents completed the Report Forms. Many investigators reported no differences or that scores were within normative limits. Van Dongen-Melman et al. in Stam et al. (2001) agreed that the majority of survivors adjusted well, but that there were serious adjustment problems in some survivors, especially boys. Twenty seven percent of survivors as compared to 10% of their healthy peers had more somatic complaints, were more withdrawn and had more social problems than their peers.

When survivors' scores were compared to normative scores, researchers could not reach agreement. Kazak et al., Levin Newby et al., Noll et al. and Lesko reported survivors' behaviour to be similar to the norm. Carlson–Green et al. and Mulhern et al. however reported more deficiencies in social competence and more behaviour problems especially related to school performance than the norm. Survivors of brain tumours and other survivors also

exhibited an abnormally high prevalence of social and behavioural problems. Teacher and parent CBCL reports were not always consistent either
(In Stam et al, 2001).

Levin Newby et al. and Sloper et al. in Stam et al. (2001) used the Rutter Behavioural Scale to measure behavioural adjustment and reported that survivors scored lower than controls on both parent and teacher rated measures. Less concentration, less academic progress and less popularity with peers were reported by the teachers. Glaser et al. in contrast found no difference in the teacher ratings, with Spirito et al. reporting more positive teacher ratings for survivors than their peers (In Stam et al, 2001).

Peer relations were investigated by Pendley et al., Spirito et al. and Vanetta et al. and reported in Stam et al. (2001). It was reported that survivors tend to have fewer friends of the same age than their peers, participate in fewer social (peer) activities and spend more time by themselves than their peers. Vanetta et al. in Stam et al. (2001) concluded that survivors of brain tumours and those who had bone marrow transplants were more socially isolated than their peers or survivors with other diagnoses. Survivors were generally found to have normal social skills adjustment (Stam et al, 2001).

Madan Swain et al. in Stam et al. (2001) investigated identity in adolescent cancer survivors. Foreclosure (no exploration, commitment) identity state was found to be most common. It is postulated that this state which involves adopting the views of significant others, may serve a protective function in assisting survivors to cope with the inherent stressors of the cancer experience.

5.3 Factors related to adjustment: Predictors of psychosocial adjustment

Stam et al. (2001) report that while only some articles reviewed are concerned with functioning in the childhood cancer survivor, most of the studies discuss the predictors of psychosocial functioning to some degree. These predictors are as follows:

5.3.1 Demographics

5.3.1.1 Gender

Stuber et al. in Stam et al. (2001) reported more PTS symptoms in women than in men, but others found male survivors to be more anxious and less socially competent than females. Van Dongen -Melman et al. reported more behavioural problems in boys (In Stam, et al., 2001).

5.3.1.2 Age

Older age at time of study appeared to be associated with worse adjustment. Older survivors reported more PTS symptoms, more psychological distress and more socio-behavioural problems. Boys over the age of 11 were also more at risk than younger boys (In Stam et al, 2001).



5.3.1.3 Single or two parent home

Mulhern et al. in Stam et al. (2001) reported that living in a single parent home was one of the factors related to more behavioural problems and Carlson et al. in Stam et al. (2001) confirmed this for survivors of brain tumours. Mulhern et al. also reported that children living in a two-parent home scored higher on psychological well-being than in single parent homes (In Stam et al, 2001).

5.3.1.4 Social class

Only Carlson et al. in Stam et al. (2001) found that social class had an effect. It is reported in this study that higher socio-economic status was associated with more adaptive functioning. Several authors found no association between demographics and adjustment.

5.3.2 Illness and treatment related factors

5.3.2.1 Age at diagnosis

Age at diagnosis is seen to be a strong predictor of adjustment. Once again conflicting results were found. Some authors report more behavioural problems, more PTS symptoms and more socio-behavioural problems in older children. Carlson et al. in Stam et al. (2001) however found the younger children to be more at risk for behavioural problems. Von Essen et al. in Stam et al. (2001) found that those diagnosed when between 10-14 years showed more depression and anxiety than those between 1-6 and 15-17 years.

5.3.2.2 Time off treatment

Together with age, this is also seen to be a strong predictor of outcome. More behavioural problems, lower self-worth, and higher perception of negative body image as well as higher social anxiety were identified in those survivors who had been off treatment for longer. More behavioural problems were found in boys off treatment for at least 5 years. In contrast with this Stuber et al. found a negative relation between PTS symptoms and months off treatment, Levin Newby et al. in Stam et al. (2001) found that time off treatment and behavioural problems were also negatively associated.

5.3.2.3 Cranial radiation

Cranially radiated patients were found to be more socially isolated than others who had undergone other methods of treatment are (Stam et al, 2001).

5.3.2.4 Predictors of PTS symptoms

Stuber et al. in Stam et al. (2001) concluded that the intensity of treatment as perceived by the patient is the most important predictor of PTSD.

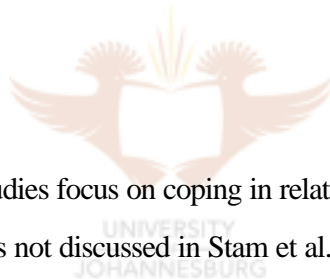
5.3.2.5 Diagnosis

Varni et al. in Stam et al. (2001) concluded that survivors who had leukaemia suffered from greater distress than other survivors did and Carpentieri et al. in Stam et al. (2001) found that brain tumour survivors displayed more problems with social competence, but had fewer behavioural problems. Very few patients with Bone Sarcomas were included in any of these studies.

5.3.2.6 Late medical effects

Late and severe medical effects led to poorer self-concept and more depressive symptoms. Physical disability or functional impairment in particular was associated with a less positive perception of personal appearance and self-concept. Athletic ability and physical attractiveness were positively correlated with social competence in BMT survivors. In several studies no illness and treatment factors were reported (Stam et al., 2001).

5.3.3 Coping resources



As has been noted before, few studies focus on coping in relation to adjustment in childhood cancer survivors and this aspect is not discussed in Stam et al. (2001). Coping is however discussed more comprehensively elsewhere in this mini dissertation.

5.3.4 Family and parental functioning

The diagnosis of cancer impacts on the whole family. The findings concerning the relation between family functioning and survivor's adjustment are discussed in the review article. Some aspects regarding family functioning are highlighted below (Stam et al, 2001).

5.3.4.1 Parental emotional adjustment

It is difficult to determine the direction of the influence as parents influence their children and vice versa.

Kazak et al. in Stam et al. (2001) found that during treatment maternal PTS symptoms impacted upon the child's anxiety, but this impact did not remain in place after treatment was over.

Sawyer et al. in Stam et al. (2001) reported that greater maternal psychopathology immediately after diagnosis was associated with a greater number of emotional and behavioural problems in the child 2 years after diagnosis. Sloper's findings concur with this (In Stam, et al., 2001).

Pelcovitz et al. in Stam et al. (2001) studied survivors 0-11 years after treatment and found that survivors PTSD status was related to their mothers PTSD status but not the mothers overall adjustment as measured by the Symptom Checklist. Stuber et al. also reported this phenomenon (In Stam, et al., 2001).

5.3.4.2 Family functioning

Most studies have looked at family functioning as an outcome, but some studies as reviewed below looked at family functioning as a predictor of survivors' adjustment.

The Family Environment Scale (FES) and the Family Adaptation and Cohesion Scale (FACES) are the two measures, which are most widely used when measuring family function. The FES looks at the underlying domains of relationships, personal growth and systems maintenance. In general it was found that family functioning in survivors does not differ significantly from control groups. Madan-Swain et al. in Stam et al. (2001) did however find that greater levels of conflict within the family correlated positively with foreclosed identity status. This is an identity state where commitment to goals and beliefs is given without a period of questioning or reflection.

Other investigators used the FACES instrument. This instrument looks at four levels of cohesion (disengaged, separated, connected and enmeshed) as well as four levels of adaptability (rigid, flexible, structural and chaotic). These two aspects are combined into types of families useful in differentiating functional and dysfunctional families. Kazak et al. and Madan-Swain et al. in Stam et al. (2001) found no significant differences between the families of survivors and the controls. Pelcovitz however concluded that survivors' parents were overly protective and highly caring,

fitting into the ' affectionate constraint' category. He further found that survivors' PTSD status was related to the perception of the family as chaotic.

Kazak et al., Lesko et al., and Rait et al. in Stam et al. (2001) found that family functioning was related to psychosocial outcomes in survivors. Family functioning was negatively associated with anxiety and PTS outcomes, while the quality of family communication; cohesion and adaptability were related to the mental health of the survivors. Family cohesion was strongly positively related to psychological adjustment, overall mental health, self-esteem and global competence.

5.4 Previous life events and adjustment by survivors

It is pointed out that dealing with childhood cancer is a dramatic life event, which could influence psychosocial functioning. Other life events can however also be contributory to and explain adjustment problems in cancer survivors and their families. Carlson-Green et al. in Stam et al. (2001) studied normative and nonnormative life events in the 12 months preceding diagnosis. The conclusion was reached that fewer negative life events caused fewer behavioural problems. Varni et al. in Stam et al. (2001) also reported that a greater number of stressful events predicted increased psychological distress and lower self-esteem.

Barakat et al. in Stam et al. (2001) observed that the objective aspects of the cancer and its treatment were not related to PTS symptoms in survivors, but that the past perceived threat to life contributed to PTS symptoms.

Levin Newby et al. in Stam et al. (2001) investigated the relationship between academic functioning and social skills and adjustment. It was concluded that there is a positive relationship between academic functioning and social skills and adjustment.

5.5 Limitations in the literature

Stam et al. (2001) conclude that although cancer survivors adjust reasonably well, the findings of the studies regarding emotional and social adjustment are inconsistent. The factors leading to this conclusion are limitations in study designs, survivors' adjustment and predictors of adjustment.

5.5.1 Study designs

The first limitation identified by Stam et al. (2001) is that the concepts measured as well as the instruments used are very wide. The instruments are further generic and not aimed specifically at issues arising out of childhood cancer. Study populations are also very diverse. Different diagnoses and treatment modalities, varied age groups and different times off treatment are included. In many studies patients with brain tumours have been excluded and in others only patients with brain tumours have been studied. Many studies have been exclusively conducted on Leukaemia patients.

Another difficulty identified by Stam et al. (2001) is that information has been gathered from a variety of sources including parents, oncologists, peers and the patients themselves. It is noted that even when the same instrument is used e.g. the CBCL, the parents' and teachers' reports differ.

Small sample sizes could also contribute to the inconsistent findings. Less than a third of the studies reviewed have more than 50 survivors as a sample. Many studies furthermore included many outcome measures with no control for type I errors despite the small sample sizes. Some studies used no control groups and comparisons with the population norms were limited (Stam et al., 2001).

5.5.2 Survivors' adjustment

Stam et al. (2001) conclude that even when the limitations noted above are taken into account, most survivors are functioning well socially and emotionally. The authors postulate that this could be due to the instruments used and suggest that more highly specific instruments are needed to assess the impact of this stressful experience.

The good adjustment could be attributed to adequate (family) coping and the use of denial, as a coping strategy can be adaptive in the case of cancer. Stam et al. (2001) posit that patients possibly maintain a high degree of optimism, which could be viewed as denial, but can also be viewed as 'selective cognitive processing' from a cognitive viewpoint and can be considered 'healthy denial'.

The concept of 'response shift', which means that the experience with cancer has changed children's conceptualisation of problems, could also possibly explain the favourable adjustment. Response shift has been described in adults with cancer as well and leads to an underreporting of problems (Stam, et al., 2001).

Sample bias is cited as the final contributory factor. Families with patients who were more severely affected may not have taken part in the studies because they did not want to face their problems. On the other hand those with more severe problems might have predominated in some samples due to the fact that they wanted to make their problems known to the study personnel (Stam, et al., 2001).

5.5.3 Predictors of adjustment

Stam et al. (2001) stress that very few studies on predictive factors relating to adjustment following childhood cancer have been done. An important predictive factor such as coping has hardly been studied. The role of family functioning in coping has also largely been neglected. The authors furthermore stress the importance of clarifying whether cancer survivors' problems are associated with cancer or other factors such as coping, family functioning and survivors' functioning at diagnosis. It is suggested that longitudinal studies of childhood cancer survivors will allow more insight into these factors.

5.6 Future research suggestions

Predictors of adjustment are seen as one of the areas for future research. The failure to accomplish appropriate developmental tasks is furthermore seen as a factor, which could increase the risk of future maladjustment in cancer survivors. This aspect has however hardly been studied and Stam et al. (2001) propose that the correlation between course of life and adjustment needs to be investigated.

Quality of Life (QoL) in adult cancer survivors has received much attention of late. QoL in children and adolescents is however a relatively new field. Although QoL is a multidimensional concept including physical, cognitive, social and emotional domains, the majority of the studies in the field of children and adolescents focus only on a few of the aspects. Stam et al. (2001) propose that the use of standardized instruments which comply with appropriate psychometric requirements is recommended. This will allow studies to be more complete and comparable. Cancer specific measures are furthermore recommended.

6 QoL and psychological stress

A central aspect of the diagnosis of cancer is that it remains a stressful and idiosyncratic event in the life of each patient as well as his/her family members with the distinct possibility of negatively influencing QoL. The diagnosis, etiological considerations and intervention strategies pertaining to

ASD and PTSD in general as well as pertaining to child and adolescent cancer patients will now be discussed. Specific reference will then also be given to trauma spectrum sequela and possible intervention strategies in a specific group of patients who have been neglected both in literature and practice. This is the group of adolescents diagnosed with Osteosarcoma and Ewing Sarcoma of the bone.

6.1 Acute stress disorder and Posttraumatic stress disorder

Individuals who experience trauma consciously or unconsciously attempt to buffer themselves psychologically from distressing thoughts or feelings which prevent them from effective functioning subsequent to traumatic event/s. Traumatic stress differs from general or cumulative stress and situational variables including expectations and perceptions of the event contribute to the potential impact of and recovery from traumatic stress (Harbert, 2002; McGarvey & Canterbury, 1998; Scott, 1997).

Although extreme trauma has long been perceived to precipitate distinct patterns of symptom responses, it was only in 1980 that the APA classified these symptoms under the diagnosis Post Traumatic Stress Disorder (PTSD). Acute Stress Disorder (ASD) as a distinct diagnosis was however only added to the Diagnostic and Statistical Manual of Mental Disorders in the Fourth Edition (DSM-IV) (McGarvey & Canterbury, 1998; Scott, 1997).

6.1.1 Diagnostic criteria

The DSM-IV-TR (APA, 2000) cites Criteria A (the stressor criteria) for PTSD to be:

A. The person has been exposed to a traumatic event in which both of the following are present:

- the person experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others
- the person's response involved intense fear, helplessness, or horror. Note: In children this may be expressed instead by disorganized or agitated behavior

Criteria A acts as a gateway to PTSD and even if a person is suffering from all the symptoms of PTSD, but the criteria of this stressor is not met, PTSD cannot be diagnosed.

The two parts of criteria A acknowledge that the stressor must be (1) objectively extreme and (2) must also be subjectively experienced as extreme (Scott, 1997).

The symptoms of PTSD are grouped under three headings: B: intrusion. The traumatic event is persistently re-experienced in one (or more) of five ways. C: avoidance. Persistent avoidance of stimuli associated with the trauma and numbing of general responsiveness, as indicated by three (or more) of seven possible ways. D: disordered arousal. Persistent symptoms of increased arousal as indicated by two (or more) of five possible ways. According to criteria E these symptoms have had to be present for and have lasted more than one month. If Criteria A-D have been fulfilled, but symptoms have lasted for more than two days and less than four weeks, with an onset within 4 weeks of the trauma Acute Stress Disorder (ASD) is diagnosed.

Criterion F stipulates that the disturbance should cause clinically significant distress or impairment in social, occupational or other important areas of functioning (APA, 2000; Scott, 1997).

In the event of PTSD being diagnosed, the following should be specified

Acute: If duration of symptoms is less than 3 months.

Chronic: If duration of symptoms is 3 months or more.

With delayed onset: if onset of symptoms is at least six months after the stressor (APA, 2000; Scott, 1997).

According to Criterion H for ASD the possibility that the disturbance might be due to direct physiological affects of a substance (e.g. a drug of abuse, a medication) or a general medical condition, is not better accounted for by Brief Psychotic Disorder, and is not merely an exacerbation of preexisting Axis I or Axis II disorder needs to be taken into account (APA, 2000).

One of the traumatic events which are specified as having the potentiality to precipitate the onset of either ASD or PTSD is that of the diagnosis of the individual or a child of the individual with a life threatening illness. The diagnosis and treatment of cancer as possible etiological factors in the onset of ASD and PTSD as well as controversies surrounding the diagnostic criteria of PTSD in the case of cancer patients (concentrating on children and adolescents) as well as cancer survivors will now be discussed.

6.2 Cancer ASD and PTSD: Etiological considerations

The prime causative factor in the development of ASD and PTSD remains the presence of a stressor. Not all people who are traumatized and exposed to a stressor such as cancer however develop the disorder. Preexisting biological and psychosocial factors as well as events, which happened after the trauma, need to be taken into account before a diagnosis can be made.

Kaplan and Sadock, (1998) posit that recent research supports the growing consensus that the development of the disorder has more to do with the subjective meaning the individual places on the stressor than with the severity of the stressor. Other aspects such as psychodynamic factors can however not be discounted in the complex etiology of this disorder. Models including the cognitive, behavioral and psychoanalytical models have been used to explain the development of PTSD following various traumatic experiences.

Supporting research in the area of PTSD and childhood and adolescent cancer will be discussed.

Stuber et al. (1997) states that the diagnosis and treatment of childhood cancer is extremely stressful. Depending on the anxiety level, subjective assessment of intensity of treatment and perception of life-threat of the child, PTSD symptoms may be mild or more severe and may or may not persist. Typical symptoms are re-experiencing the traumatic event (flashbacks), intrusive thoughts, numbing or hyperarousal of emotions, avoidance of reminders of the traumatic event, hypervigilance, increased startle response, etc. Children in particular may be prone to physical symptoms, e.g. stomach aches, nightmares, etc. Predictors of PTSD in children include the child's characteristics such as age and sex; exposure to other traumatic events, access to social support and coping style (e.g. positive, blaming, etc.).

Stevens, Mahler and Parkes (1998) concur with other authors that due to successful treatment of childhood cancer, the number of adult survivors of childhood cancer are increasing. These people may be at increased risk of grave health problems in the long term because of cancer treatment. This study used a population of 290 adult survivors with the most common primary diagnoses being acute lymphoblastic leukaemia (33%) and Hodgkin's disease (15%). Chemotherapy was used in 85% of the group, radiotherapy in 81%, surgery in 48% and all three in 28%. Fifty eight percent of the group had at least one long-term medical problem, and 32% two or more medical problems, e.g. infertility, nephrectomy, thyroid hormone deficiency, etc. The purpose of this study was to document the late/delayed effects of cancer treatment in adult survivors under routine follow-up surveillance. Some of these effects may not become apparent before adulthood, e.g. infertility, cardiotoxicity and second malignancy. The treatment normally determines the late effects experienced, and not the diagnosis.

Psychosocial late effects such as anxiety regarding recurrence, relationship problems, learning disabilities, depression and PTSD are difficult to pick up during routine medical examinations in

a busy follow up clinic and are often neglected in these settings (Stevens, Mahler & Parkes, 1998).

In thirty one percent of the survivors assessed for anxiety and stress symptoms by Thomas et al. (1997) anxiety levels were as high as in patients with active disease. Fear of recurrence was mostly cited as being the reason for the anxiety. It was furthermore found that this anxiety seemed to be persistent even after discharge from the clinic in terms of follow up.

In an extensive literature survey on PTSD in response to cancer conducted by McGrath (1999) it is suggested that acute or long-term stress reactions in patients with cancer have been neglected as a field of study. She postulates an underreporting of PTSD within the cancer population because studies on psychological sequelae have focussed almost exclusively on affective distress such as anxiety, anger and depression and has excluded acute or long-term stress reactions. The instruments used in such studies can further mask or obscure indications for ASD or PTSD. In paediatric oncology disorganised and agitated behaviours in children can be overlooked as normal reactions without cognisance being given to the severe stress reaction underlying this behaviour. Other researchers cited by McGrath (1999) reiterate that the use of standard measures for anxiety and depression have been blocks to documenting possible long term PTSD as a late sequelae in the survivor population. The same can be said for adult studies.

According to McGrath (1999) studies concerned with the factors, which increase the individual's vulnerability to developing PTSD whilst being treated for cancer, are filled with contradiction and inconsistency. Arguments arise around such factors as age, marital status, and family support, issues associated with severity of illness and treatment, and previous physical and mental health. A further drawback is an under-reporting even when the focus of a study is stress.

Nonetheless certain predictive factors were identified. These predictive factors viewed by McGrath (1999) as being prognostic in the oncology setting are:

- Lack of social support
- Experiencing a succession of traumatic events such as loss and grief
- The buffer of material and financial comfort
- Severe symptoms and side effects from treatment
- Recurrence of disease
- Prolonged hospitalisation
- History of PTSD in family
- Major difficulties in life besides the cancer
- Younger age during diagnosis and treatment
- Anxious personality
- Perceiving life to be difficult and unsatisfying

Tierney (2000) validates certain of McGrath's (1999) findings when she refers to considerable previous trauma research. The research cited has found that family support will help prevent the development of PTSD in children within the context of a traumatic event. The presence of parental distress or the incidence of parental psychiatric disorders however predicts a higher incidence of PTSD in children.



Factors such as gender (girls report more PTSD symptoms than boys) as well as the perceptions of life threat and treatment intensity by the mother of the patient are cited by Stuber et al, (1997) as being predictive of the development of PTSD in children with cancer.

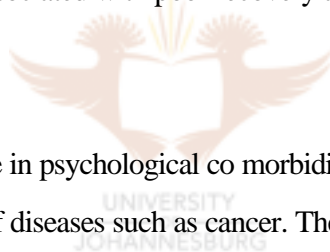
Rourke, Stuber, Hobbie and Kazak, (1999, p.130) summarize the findings of etiological research on PTSD diagnosis and childhood cancer as follows. " the development of symptoms in all groups was related to anxiety, to perception of treatment intensity and life threat and to social support."

Controversies such as the according of clinical status to what is viewed by some as common or normative reactions to traumatic events and the 'imposition' of western views on non western

cultures remain relevant when attempting to develop an etiological model of PTSD. It has furthermore been proposed that treatment of reactions to traumatic events as a psychiatric illness minimizes and undermines personal responsibility and resilience (de Silva & Yule, 2001).

Bessel (2001) argues that although cancer survivors do exhibit remarkable resiliency, general psychological distress regarding social anxiety, poor peer acceptance and self-perception issues is present in many individuals. She believes that appropriate support, interventions and guidance will help each child with cancer succeed and reach their full potential.

As the number of survivors increase, the need for psychosocial supportive intervention programs in general, but also in terms of ASD and PTSD is becoming greater. McGrath (1999) quotes studies, which illustrate the need for preventative interventions, both during and after treatment for cancer. Many patients and their caregivers only exhibit symptomatology long after the ordeal is over. This is associated with poor recovery and avoidance of further medical treatment.



Vessey (1999) reports an increase in psychological co morbidity concurrent with the increase in chronicity (as opposed to fatal) of diseases such as cancer. The exact incidence of co morbidity is not known, but the impact of mediating factors such as family support and parent and child perceptions and expectancies is once more stressed.

Voelker (2001) reports that apart from the trauma of having a life-threatening illness, the treatment of cancer can also be traumatic. Survivors of childhood cancer also seem have a vulnerability toward developing PTSD. One in five young adult survivors of cancer show symptoms of PTSD. A study done among 78 young adults aged between 19 and 40 showed a rate of PTSD four times higher than individuals aged between 9 to 17 years. Particular vulnerability factors in this age group include the establishment of long-term interpersonal relationships and a focus on the establishment of careers. These factors seem to aggravate the symptoms. Anxiety, avoidance behaviour and intrusive thoughts were of the most common symptoms found in this study. A sense of ‘sustained threat’ in their lives was also reported.

Smells or other events associated with the trauma often seemed to trigger anxiety even many years after diagnosis.

Rourke, et al (1999) propose that a model of posttraumatic stress where cancer and its treatment are viewed as life threatening events explain ongoing symptoms in adolescent and young adult survivors of pediatric cancer. When pediatric and adolescent cancer and the associated treatment is conceptualized as a traumatic experience for the child and his/her family at diagnosis, an expectation and an understanding for certain reactions is allowed for. The knowledge that these reactions might and do recur at transitional periods such as the transition into young adulthood can help medical staff and families to develop and participate in programs which address this issue.

Normal development requires conscious life choices of the individual. Childhood and adolescent cancer survivors however need to revisit the cancer experience in order to integrate the past with future possibilities. These young adults may re-visit traumatic events and may even understand and re-experience traumatizing events for the first time with new cognitive insights into the loss they may have suffered (e.g. Late effects such as infertility). Very little research has been done in this area, but it appears that young adults experience a great deal more anxiety with significantly more avoidance behavior and intrusive thoughts than their younger counterparts. Rourke, et al (1999) stress the importance of understanding the predictors and prevalence of PTSD symptoms in this population group. They reiterate that there is a subset of cancer survivors who experience ongoing psychological difficulties and that ongoing research in this area is imperative.

Madan-Swain et al. (2000) confirm PTSD symptoms related to the cancer experience and family functioning in their study of 52 cancer survivors ranging from ages 12 to 23 and their families. Identity formation in adolescent survivors of childhood cancer was studied. These writers suggest that the data provides additional information regarding the association between PTSD symptoms and family functioning and foreclosed identity status. A possible explanation is

that PTSD symptoms may increase the structured and restrictive style of the families. This restrictive style may in turn limit the change that is imperative to an adolescent's development of identity. Because the families seem to be more rule bound and role governed they may be less able to accommodate the developmental tasks of the adolescent.

Erickson and Steiner (2000) support the development of the concept of a trauma spectrum model and trauma adaptation in long term cancer survivors. These authors confirm the high incidence of somatic symptoms and other trauma spectrum distress related evidenced in some survivors of childhood and adolescent cancer years after active treatment has been completed. They also stress the importance of risk factor identification in this population as this has important implications for intervention strategies.

Erickson and Steiner (2000) acknowledge that somatic symptoms in cancer survivors do not always have a psychological base, but that the significance of these symptoms cannot be underestimated. Participants in their study who tend to report more somatic complaints also tend to report other types of non physiologically based trauma-related distress. The vast majority of participants in this study reported at least partial current PTSD symptoms and a repressive adaptive style. This style includes low levels of reported psychological distress and heightened levels of restraint. It is suggested that somatic symptoms may represent an important area of initial assessment and as an indicator of other trauma related distress as survivors are comfortable with reporting these symptoms.

Most of the research cited concentrates on PTSD and the cancer experience. Due to the relatively recent addition of ASD as a diagnostic criteria, it would seem that research into ASD and the young cancer patient is very limited. In a study performed by Mc Garvey and Canterbury (1998) it is however proposed that identification of ASD is difficult due to the dissociative symptoms which characterize this disorder. These symptoms including avoidance and inability to communicate emotional distress might lead to the medical staff not being aware of the patient's anxiety.

The premise that exposure to trauma is the only exclusive risk factor for PTSD has led to the neglect of conceptual and empirical risk indicator and risk mechanism research. Prior trauma and the predictive utility of ASD in identifying those individuals at risk for PTSD are proposed as being important in future PTSD research. The difficulty and controversies surrounding efficient and adequate psychological assessment of children and their families at time of diagnosis as well as during and following treatment remains a stumbling block to the identification of accurate etiological factors (Cohen, 1998; Litz, Gray, Bryant & Reed, 2002).

A possible etiological model is proposed in this mini dissertation and is based on the above literature (Appendices A & B). It is important to note that this model may fit for children and adolescents exposed to similar events such as the diagnosis of other life threatening or chronic diseases which require intrusive and chronic treatment. The direct applicability to acute horrific pediatric events such as sexual abuse, motor vehicle accidents or interpersonal violence may however be limited.

6.3. Patients diagnosed with Bone Sarcomas

There are two unique aspects, which need to be examined when Bone Sarcoma Patients are studied. These are the fact that all these patients undergo major surgery, often with mutilating effects together with very high dose chemotherapy and that the vast majority of patients are adolescents at time of diagnosis (Kaste, Neel, Rao, Thompson & Pratt, 2001; Yasko, Reece, Gillis & Pollock, 1997).

6.3.1 Unique concerns: Treatment of patients with Bone Sarcoma

Patients with Bone Sarcomas seem to be especially vulnerable when it comes to physical disruptions and possible psychosocial late effects. They inevitably undergo either limb salvage surgery or the amputation of a limb together with six to eight cycles of neo adjuvant

chemotherapy. When patients with Bone Sarcomas are evaluated the advent of limb salvage surgery has brought about various emotional and functional concerns not associated with amputation. (Up to 15 years ago amputation was the only surgical intervention available for this disease.) These patients live with a prosthetic implant in their limbs for the rest of their lives. The concerns with which they are faced include the risk of infection in the prosthesis followed by possible amputation as well as the fact that the patient is never again allowed to participate in contact sport after such surgery. Adolescents who used to excel at sport or ballet find it especially difficult, as they no longer 'fit' into the group concerned. Issues such as limb length discrepancy and nerve damage, combined with other aesthetic aspects such as long unsightly scars seem to be of particular concern to the girls and young women. Whereas patients with other cancers are followed up for 5-10 years, these patients need to follow up at the Orthopaedic surgeon for the rest of their lives. The prosthesis acts as a reminder of their cancer throughout their lives (Lindeque McLoughlin, Grobbelaar & Schoeman 1997).

When the literature pertaining to the functional and psychosocial evaluation of Bone Sarcoma patients is perused, the various emotional and functional concerns associated with limb salvage surgery or amputation are not fully addressed in most publications. Concerns specific to Limb Salvage surgery include the risk of infection in the prosthesis followed by possible amputation. Body image issues also seem to be of particular concern to this group of patients. Because no single effective instrument measuring the specific psychosocial concerns is available for this group of patients, these concerns are largely neglected in functional evaluation as well as quality of life evaluation. When primary amputation is the treatment of choice body image and self-esteem as well as sexual issues seems to feature prominently (Bland, 1997; Lindeque et al., 1997; Maguire & Parkes, 1998; Payne, Lundberg & Brennan, 1998; Rougraff, Simon, Kneisl, Greenberg & Mankin, 1994; Shchurovsky, 2001; Shell & Miller, 1999; Yasko et al., 1997).

Lane, Christ, Khan and Backus (2001) however reviewed current orthopedic literature and they present the results of several studies, which attempt to address the psychosocial issues in more detail. These studies reflect both functional as well as psychological effects of both limb

salvage surgery and amputation upon patients treated for Osteosarcoma. The writers conclude that both sets of patients report quality of life problems, which include difficulty with health insurance, employment problems, social isolation and poor self-esteem. It is suggested by Lane et al. (2001) that each patient should not only receive individualized care regarding a surgical plan, but also regarding psychological and social adjustment after surgery. Careful pre-surgical preparation, identification of post surgical traumatic stress symptoms and the accessibility to quality prostheses are suggested as being useful in order to improve adaptation. The same principles are proposed by Noll, Pawletko and Sulzbacher (1993).

Martz and Cook (2001) confirm the above in a study where it was found that persons with amputations are more susceptible to psychosocial effects such as PTSD than those with heart failure or those who do not suffer physical impairments. PTSD can also have an impact on rehabilitation with respect to e.g. foreshortened sense of the future in these patients. The rehabilitation professional may attempt to facilitate discussion about future career or educational options and the patients may not be able to imagine these options. Because this is often a first and vital step in physical rehabilitation, the process may be jeopardized.

Yasko et al. (1997) stresses that although quality of life remains difficult to define, effective and improved measures for documenting the impact of the above treatment is needed. Their study revealed that amputees report difficulties with self-esteem and socialisation more frequently than those patients who had undergone limb salvage procedures. Shell and Miller (1999) who investigated the long-term effects of amputation on sexuality support this view. Amputees report a low self-esteem and poor body image due to the amputation. This in turn causes them to experience both physical and psychological problems pertaining to sexuality and sexual intercourse. The authors mentioned above express the need for specific assessment techniques and interventions.

Because no effective instrument measuring the psychosocial concerns for patients with bone sarcomas is available, aspects such as ASD and PTSD are largely neglected in functional

evaluation as well as quality of life evaluation (Lindeque, et al, 1997; Bland, 1997; Payne et al., 1998 and Yasko et al., 1997).

The international protocol for the treatment of bone sarcomas includes the use of both surgery and high dose chemotherapy. Exposure to high dose chemotherapy is also predictive of somatic distress in cancer patients (Lindeque et al., 1997; Zebrack, et al, 2002). It is thus postulated that the patient diagnosed with a bone sarcoma could be particularly vulnerable to ASD and PTSD.

6.3.2 Adolescence and cancer

The second unique characteristic of patients with Bone Sarcoma is that diagnosis is usually made during the second decade. Adolescence is generally described as a phase of development, which is unique along life's continuum. This is seen as being mainly due to the many transitions, which take place during this phase. It is the phase between childhood and adulthood and usually lasts from the ages of 10 - 13 to approximately 18 - 20 depending on the developmental theory used as descriptive base. The adolescent experiences biologic, psychological and physiologic changes at a rapid rate during this time. Young people of this age are changing and changeable. Achieving a sense of identity and a degree of independence in preparation for assuming an adult role in society are crucial to this phase of development. A sense of control is thus very important during this phase of life (Barr, 2001; Coleman & Hendry, 1999; Glover, 2000; Goldberg & Tull, 1984; Hinds & Quargnenti, 1999; Kalafatich, 1975; Rauck, Green, Yasui, Mertens & Robinson, 1999; Rowland, 1989).

Many authors stress the importance of peer group membership and support in order for the adolescent to fulfil the developmental milestones and to be able to negotiate transitions during this period. Due to the disruptions of cancer diagnosis in adolescence peer group interactions may be disrupted and lead to further psychosocial stresses in the adolescent cancer patient (Barr, 2001; Coleman & Hendry, 1999; Ettinger & Heiney, 1993; Firshein, 1999; Goldberg &

Tull, 1984; Hoag & Burlingame, 1997; Jackson & Warren, 2000; Kalafatich, 1995; Katz & Varni, 1993; Millstein, Nightingale, Peterson, Mortimer & Hamburg, 1993; Wright et al., 2001).

6.4 Early intervention and treatment programs: ASD and PTSD.

Harbert (2002) proposes that early therapeutic intervention has as one of its goals to prevent the natural reaction to trauma or ASD from becoming uncontrollably intensified and also possibly from developing into PTSD. This author suggests that the approach should include a warm and empathetic environment for the person to tell their story. This should then be coupled with an educational approach where physiological and psychological effects of trauma are discussed. Booklets or other reading materials can also be given to the person. Social integration strategies such as family and group psychotherapy are also advocated. This can reduce the patient's feelings of isolation and also reinforce coping methods.

6.4.1 Children and adolescents: PTSD - intervention strategies.

Due to the limited empirical support for various treatment approaches for children there is limited consensus among experts in the field as to treatment hierarchy. There is however agreement on the essential components of appropriate intervention strategies for children with PTSD. These components are :

- Direct exploration of the trauma
- Use of specific stress management techniques i.e. deep muscle relaxation, thought stopping or positive imagery
- Exploration and correction of inaccurate attributions regarding the trauma
- Inclusion of parents in treatment

(Cohen, 1998)

There is little empirical evidence comparing efficacy of group versus individual therapy for children with PTSD. It is however proposed that a trauma focussed approach which treats the child's specific symptoms is more important than the modality. The use of psychopharmacological drugs in the treatment of PTSD in children remains a debatable topic. In co-morbid situations medications should be selected on the basis of established practice in the treatment of such co-morbid conditions i.e. prominent depressive, panic and/or ADHD symptoms (Cohen, 1998).

In Long-term coping (2000) it is suggested that poor coping can often be ascribed to more severe cancer, treatment effects lower intellectual ability and a shorter time of remission; also longer treatment tends to promote poor coping. It is however stressed that long-term coping is determined by multiple factors with a complex interplay between medical and demographic as well as intellectual background variables. An intervention strategy needs to take all of these factors into account.

MacFarlane and Yehuda (2000) postulate that many of the treatment programs and suggestions surrounding treatment of PTSD evolved when the diagnosis was still in its infancy. The efficacy of early preventative intervention has for example been questioned in recent years. Current concepts in posttraumatic treatment do however not appear to deal with the transitions of symptoms from the normative to the maladaptive processes. These authors posit that it is imperative to determine which of the acute stress reactions are the prodromal stages of the posttraumatic process and then to determine which of these processes need definite therapeutic interventions. It is also imperative to consider whether traumatic reactions to different events are likely to be amenable to the same treatment interventions. As such treatment modalities need to be tailored to fit specific considerations.

The above considerations all need to be taken into account when designing treatment protocols for child and adolescent cancer patients and survivors.

As mentioned before, many studies pertaining to cancer patients and intervention programs concentrate on quality of life issues regarding groups of cancer patients other than adolescents or sarcoma patients. Interventions aimed at the disease period only are also the most common programs described and post active treatment programs are lacking. (Craven, 1996; Mackie, et al., 2000; Roberts, Piper, Denny & Cuddeback, 1997).

Most studies furthermore make use of a strong medical model of investigation, with many structured questionnaires and control groups. These studies also often concentrate upon quality of life evaluation without proposing intervention programs.

As the number of survivors increase, the need for supportive intervention in general, but also in terms of PTSD is becoming greater. McGrath (1999) quotes studies, which illustrate the need for preventative interventions, both during and after treatment for cancer. Many patients and their caregivers only exhibit symptomatology after the ordeal is over. This is associated with poor recovery and avoidance of further medical treatment.

McGrath (1999) concludes that the assumption that many patients will share a common response to cancer is being validated by current research. This includes painful aspects of intrusion, avoidance, numbness and hyper-arousal. She expresses the hope that research in the area of PTSD and cancer will evolve and that afflicted individuals can be reached with the message that such a reaction to trauma is not pathology, but an expected and remedial aspect of the cancer experience. Therefore creative solutions are needed both pre-and post treatment.

6.4.2 Intervention Programs described in literature.

Stuber et al (1997) proposes that the most valuable interventions for PTSD in childhood cancer would be during the active treatment phase. During this phase there is more quantity and quality interaction between the staff and the patient and family than during any other phase of treatment. Parents' and childrens' perceptions of the diagnosis and its impact are formed during this period.

The development of a realistic but hopeful understanding of life threat and the reduction of perceptions around treatment intensity can be developed here. Adequate and developmentally appropriate explanations and preparations for procedures should be included in the program. Special care should be taken with overtly anxious parents and children as well as those who are experiencing significant additional life stressors. Because many long term survivors continue to present with PTSD symptoms years after active treatment has ceased, the follow up care needs to be designed in such a way that this issue can be addressed at these times.

Two South African studies: Boermeester (1996) and Van Rooyen (1993) highlight the need for supportive programmes in South Africa. Both these writers as well as Ries (1996) stress the importance of patient support groups in the promotion of quality of life and well being of cancer patients. Berard and Boermeester (1998) also stress the importance of age appropriate patient support groups in the promotion of quality of life and well being of cancer patients.

Mastrovito, Moynihan and Parsonnet (1989) stress the importance of self-help and mutual support groups in the treatment of cancer patients. Studies of crisis theory, coping strategies and social support systems theory have validated the use of support groups in the psychotherapeutic programs for cancer patients. The writers do however stress the need for empirical research into the effectiveness of such programs for various psychosocial sequelae such as PTSD.

Roberts et al. (1997) propose that an intervention consisting of a professionally supervised support group combining group therapy with psycho-educational strategies are useful in young adults with cancer. Anxiety about physical health, worries about being able to have children, relationship issues and financial problems should be addressed. Psychological wellbeing improved in a pilot study, but no changes are indicated regarding coping mechanisms or overall quality of life.

Young cancer survivors are often socially more isolated and they have fewer intimate relationships than control groups of the same age. The diagnosis and treatment of cancer can

hamper developmental tasks in many ways as well. Financial dependence may also become an issue for young adult patients. Furthermore, there may be grief over the possible loss of life and the opportunity to reach one's full potential. The article describes a pilot program in which 14 young adults with a variety of diagnoses were given the opportunity to attend a support group for six weeks. Both qualitative and quantitative data pertaining to effectiveness of support group interventions is presented. Although this program showed positive results, no follow up reference could be located (Roberts et al., 1997).

Schwartz, Feinberg, Jilinskaia and Applegate (1999) report on the impact of psychosocial treatment on 22 young adult survivors. The response shift effect was reflected in both changes in internal standards and also values and conceptualisation of quality of life. The intervention appeared to normalise the survivors' conceptualisation thereof.

Bauman, Drotar, Leventhal, Perrin and Pless (1997) published an extensive literature review and analysis of psychosocial intervention programmes for children with chronic conditions. The review spans the years 1979-1993. Fifteen programmes are described with only three being interventions for children with cancer. Most of these studies seem to be problematic in that they were inadequately reported and poorly described, with very small population groups. These authors conclude that, although programmes are being devised and implemented, acceptable evaluations and a strong theoretical base are necessary in the future.

Danielson, Hamel-Bissel and Winstead-Fry (1993) suggest family intervention as an effective way of dealing with and preventing possible psychosocial difficulties at a later stage. During the illness situation the health care professional should assist the family in developing coping styles, which assist all the members of the family to be prepared for and deal with the emotional reactions such as anger, fear and confusion, which accompany each stage of treatment.

It is important for a family to function as a unit, especially in times of crisis. Through family therapy, any maladaptive patterns in this regard can be addressed. Anxiety is usually heightened

by lack of knowledge, information and misunderstanding. Through education and the fostering of open communication between the staff and family members, as well as within the family, this anxiety can be reduced. Emotional support by others can also be facilitated by the health care professional (Bradwell & Hawkins, 2000; Danielson, et al., 1993).

Henderson (1998) reports that therapy can and does help cancer patients who show symptoms of PTSD. Flashbacks and a sense of hopelessness are common among depressed cancer patients. One hundred and thirty cancer patients and he observed painful, recurrent memories, often related to illness and death or sometimes more specifically to cancer. However, therapeutic techniques such as confronting and “reinterpreting” the traumatic events in a positive way may be helpful in treating such patients.

Stress management techniques are very individual; what works for one person, may not work for another. Strong moods and feelings are often felt by someone who has survived a life-threatening illness; identifying these moods and feelings and being aware of stress is important – also awareness of body tension in different parts of the body. Techniques to manage stress include assertiveness training, autogenics, biofeedback, cognitive behavioural approaches, exercise, meditation, progressive relaxation, self-hypnosis, guided imagery, etc. (Kreidler, Zupancic, Bell & Longo, 2000).

Miller (1999) covers specific diagnostic and treatment issues pertaining to PTSD. Not only the patient, but also family members and other persons close to the patient will be affected to a greater or lesser extent. The effects of trauma on the family are classified into four types:

- Simultaneous effects (e.g. natural disaster affecting the whole family)
- Vicarious effects
- Chiasmal effects (traumatic stress affects all family members)
- Intrafamilial trauma (e.g. where traumatic experience comes from within the family, e.g. child abuse).

Cancer trauma may be viewed as falling under chiasmal effects and the following strategies are suggested.

Treatment strategies may be divided into five phases:

- 1) Building commitment to the therapy objectives
- 2) Deciding how the problem is viewed
- 3) Reframing the problem
- 4) Developing a “healing theory” for the family
- 5) Closure and preparedness

(Miller, 1999)

In order to minimize the effects of the trauma of a cancer diagnosis during these phases, an individually tailored program needs to be implemented in each case. The treatment strategies specifically geared toward minimizing and treating ASD and PTSD in such a program include the use of various combinations of medication and/or psychotherapy techniques such as:

- Psycho education
- Anxiety management techniques - relaxation training, breathing retraining, positive thinking and self-talk, assertiveness training, thought stopping.
- Cognitive therapy
- Exposure therapy
- Play therapy (Foa, Davidson & Frances, 1999)

The psychotherapy technique/s, which are most suited for each individual, his/her symptoms as well as family situation and predisposing factors need to be carefully chosen at the various stages of the disease. The applicability of family/group or individual therapy also needs to be reviewed continuously.

Staff debriefing and counseling can also never be forgotten in an oncology setting as the staff members are often traumatized by the radical treatment protocols which these patients often need to undergo.

The writer would furthermore concur with Stuber et al. (1997) that treatment for ASD and PTSD is most valuable during the active treatment phase, but it needs to be stressed that ongoing monitoring of the individual patient's 'trauma status' needs to be done. The number of survivors who did not receive any psychotherapeutic intervention during the active treatment phase and are now entering transitional life phases such as marriage is large. These patients do come for follow up consultations to the various clinics and need to be 'picked up' here.

Due to the growing acceptance of qualitative and postmodern approaches in psychology research, such studies are also being published in the literature more frequently. Penn (2001) suggests an intervention strategy based upon the narrative approach when dealing with families who need to cope with a chronic illness such as cancer has become. In this postmodern approach the illness is first of all regarded as being relationally traumatizing for both the patient and the family. The term relational trauma is used because most members of the wider system display signs of physical stress, isolation and helplessness. With the emphasis on language, conversation and story telling (oral and written) an intervention is devised whereby the members of the system's voices are reconstituted through writing. The emotions, which have been displaced by the illness, are then restored to the conversations. Penn (2001) suggests that this kind of intervention could be considered for certain families who would be open to a 'non traditional' way of therapeutic intervention.

6.5 Trauma, cancer and meaning making

Vickberg (2000) explores whether global meaning in the life of a cancer patient may have a positive impact upon the frequency and impact of intrusive thoughts. The rationale being that if the patient believes his /her life has purpose and order, the distressing effects of intrusive

thoughts can be counteracted. A study was performed using long term breast cancer survivors and the findings confirm those of other studies in this regard. Vickberg (2000) suggests that both frequent intrusive thoughts and low global meaning play important roles in the maintenance of psychological distress after stressful events. She encourages future research in order to develop programs whereby survivors can be equipped to better deal with intrusive thoughts through the finding of global meaning.

Viktor Frankl suggested that the need for meaning is a crucial and primary motivating force in people's lives. This need may be especially critical during traumatic experiences. Greenstein and Breitbart (2000) cite a study performed by Moadel (1999) in which as much as forty percent of cancer patients sampled reported wanting help with finding a sense of meaning in their lives.

Everyone can be expected to face an existential crisis at some point in life. Younger cancer patients and their families however need to deal with the issues of pain, loss and death sooner and often more intensely than others do. The diagnosis of a potentially fatal disease may be seen as a crisis in the fullest sense of the word. This experience may in turn offer an opportunity for growth and meaning as one learns to cope. Positive psychosocial changes and an improved sense of meaning in life have been associated with the diagnosis as well as bone marrow transplants in various studies. The ability to find meaning in traumatic events, has also been associated with an increased ability to adapt to them without suffering undue psychological distress. (Greenstein & Breitbart, 2000).

Sources of meaning as stipulated by Frankl are used in group therapy interventions by Greenstein and Breitbart (2000). The sources are: creativity, experience of relationship and beauty (incorporating social support and humour) as well as attitude and fortitude (this includes coping mechanisms such as gaining a new perspective on life and focussing on what is really important).

6.5.1 Existential issues: adolescent cancer patients and survivors

In an extensive literature survey minimal relevant literature could be located regarding existential issues and adolescent cancer patients. The relevant literature will be briefly discussed.

Berard and Boermeester (1998) and Rowland (1989) agree that adolescents tend to think about life in a philosophical way and they soon become acutely aware of the seriousness of their illness and its meaning for the future. The uncertainty of prognosis leads to fears of recurrence much more often than in younger children. Anxiety, panic or depression may occur when their mortality is faced. The illness and possible recurrence may be viewed as a punishment from God or as means of punishing others. The adolescent's confrontation can however also precipitate a search for meaning of life. Survival may be associated with guilt or alternatively special purpose in life. In some adolescents their faith in God is a source of strength and they are able to adapt to other losses more easily. The peer group associated with the individual's church is also often a major source of social support for the adolescent.

7. Psychosocial adaptation and resilience

One aspect central to the study of psychosocial adaptation and also the development of intervention strategies for adolescent cancer patients should be the understanding and acknowledgement of the role resilience plays in psychosocial adaptation during and following the diagnosis of cancer.

In the field of Paediatric Oncology Nursing there has been an increasing awareness and interest in researching the area of resilience in the adolescent cancer patient. Woodgate (1999a and

1999b) proposes a conceptual model for resilience, which is relevant to the adolescent with cancer. She furthermore reviews the literature related to resilience and the adolescent cancer patient. She also aims to provide an understanding of the factors, which contribute to this resilience.

7.1 A resilience centred approach

Woodgate (1999a) points out that the shift from a deficit centred model to a more optimistic one in the 1990's played a large role in a push to see the child with a problem not as deviant individuals, but as ordinary people in exceptional circumstances. This view led to much research pertaining to resilience in adolescence including the adolescent with cancer.

Woodgate (1999a) proposes that a resilience-centred approach leads to hope and optimism being injected into experiences where stress and adversity abound. By researching resilience Woodgate (1999a) furthermore suggests that the researcher can gain more insight into maladaptive behaviour by understanding how an individual deals with stress and adversity. She continues to suggest that maladaptive and adaptive behaviours are not dichotomous but exist on a continuum. An understanding of resilience will thus lead to a more comprehensive understanding of the adolescent cancer experience.

7.2 Definitions of resilience

Woodgate (1999a) points out that the term resilience is complex and thus difficult to define simply. She suggests that resilience as pertaining to the adolescent cancer patient be viewed from various standpoints and then synthesized into a theoretical model.

Firstly the adolescent cancer patient who is resilient is described as someone who (1) possesses certain traits, (2) engages in certain actions and (3) has certain resources available. Resilience can also be viewed as an outcome. Three types of well-documented resilience phenomena can

pertain to adolescent cancer patients. They are: (1) good outcomes in high-risk children, (2) sustained competence in children under stress and (3) recovery from trauma. The third way to view resilience is as a process, which is affected by protective and vulnerability factors. This process may include traits and outcomes. Woodgate (1999a) points out that viewing resilience as a process allows for a more comprehensive understanding of the concept and also acknowledges that resilience can be learned by the individual. She does however stress that this way of conceptualising resilience requires detailed, longitudinal research in order to understand the mechanisms involved more fully.

Concepts, which need to be understood in the context of adolescent cancer, are what it means to “spring back” or “bounce back”. Woodgate (1999a) views bouncing back as the ability to bend; yet to subsequently recover, allowing for the potential for growth.

Woodgate (1999a) stresses that resilience should not be confused with the idea that individuals who are resilient cannot be hurt or wounded.

Definitions for the constructs of coping, competence and hardiness tend to overlap with definitions for resilience. Woodgate (1999a) suggests that coping be viewed as a component or sub construct of resilience.

7.3 How resilience develops in adolescents with cancer

The model of resilience proposed by Woodgate (1999a) is based on various theoretical underpinnings including those of Rutter and Gramezy. The main components of the model are (1) stressors or risk situations, (2) protective and vulnerability factors and (3) outcomes.

7.3.1 Stressors and risk situations

Five specific categories of stressors (particular events or situations which evoke an emotional reaction) can be applied to adolescent cancer patients. Loss, chronically disturbed relationships, events that change the family status quo, events which require social adaptation and acute negative events such as physical trauma. These stressors may be as a result of the disease itself or major developmental changes, which occur during the critical period of adolescence. Stressors may be acute e.g. lumbar punctures or chronic e.g. changes in the family system (Woodgate, 1999a).

Psychic trauma may furthermore occur due to the illness and its treatment. Woodgate (1999a) however stresses that the individual will only become traumatised if he or she feels utterly helpless during the even or events. The adolescent with cancer thus has the potential to be resilient if they do not feel totally helpless in the decision making process.

Normative developmental tasks and stressors occur concurrently with the cancer diagnosis and treatment. Adolescents can thus experience a 'dual crisis' when diagnosed with cancer (Woodgate, 1999a).



7.3.2 Protective and vulnerability factors

Protective factors refer to influences, which modify or alter a person's response to stressors. They provide resistance to stress and encourage patterns of adaptation and competence. Three broad categories of protective factors have been described (1) personality features such as self esteem and coping strategies, (2) family cohesion and an absence of discord and (3) the availability of external support systems which reinforce coping efforts (Woodgate, 1999a).

Vulnerability factors act to intensify the person's response to a risk situation. These factors are not as clearly defined as protective factors. It is difficult to distinguish between vulnerability factors and direct stress factors and one occurrence may act in both these capacities. The

amputation of a limb in bone sarcoma can be seen as a direct stressor, but also as a vulnerability factor, predisposing the adolescent to vulnerability for other stressors (Woodgate, 1999a). It is also important to remember that the cancer forms part of a process of development with a complex range of happenings both before and after the diagnosis. The developmental link is stressed by Woodgate (1999a) and she points out that the individual will deal with the same stressors in different ways at different ages.

7.3.3 Outcomes

The experience of resilience is dynamic and the individual may be resilient, but will occasionally exhibit a maladaptive response before achieving successful adaptation. Resilience can result in increased quality of life, but increased quality of life can in turn lead to increased resilience to stressors. Woodgate (1999a) points out that even if competence and resilience are present, the adolescent may still have a variety of psychosocial difficulties such as depression or anxiety at times.

7.4 Resilience in the Adolescent Cancer Patient

The literature review used by Woodgate (1999b) to reach her conclusions includes 36 studies. The age range studied was 10 to 21 years and those studies which included preschool and younger children together with adolescents were excluded for the purpose of the conclusions, as most of the findings did not identify clear developmental differences between the adolescents and the younger children. The main areas covered were (1) stressors, (2) protective and vulnerability factors and (3) outcomes.

7.4.1 Stressors associated with the adolescent cancer experience

It was found that adolescents appraised more events as stressful than younger children and they were also more bothered by limitations on age appropriate activities than other children.

Woodgate (1999b) points out that stressors related to their cancer are numerous in adolescents. These include fear of treatment, fear of treatment related side effects, life changes and being treated differently. They also have concerns about school and career as well as the physical changes, which occur. Existential issues become a concern as well. Because the majority of studies reviewed looked at cancer as one stressful event, specific events related to the cancer experience were rarely examined as individual stressors. Each individual's experience is unique due to diversity in symptoms, treatment, pain and related events. Recent studies reveal that adolescents describe pain and especially treatment related pain as being one of the most stressful things about having cancer.

Woodgate (1999b) states that one of the main concerns about the studies performed in the area of stressors is the lack of recognition of interaction between non-cancer related stressors such as family and peer issues and cancer stressors.

7.4.2 Protective and vulnerability factors affecting responses to cancer

7.4.2.1 Self-concept

Self-concept, self-esteem and self-understanding have been identified as being critical to the individual's mastering of the difficult situations related to cancer. Although these aspects have mostly been studied as outcome responses and not as protective variables, there are resilience studies in which these concepts have been identified as being centrally important to the resilience of the adolescent with cancer. It was further shown that adolescents need to know and be shown that they have not changed, but are still the same person. Being accepted by members in their social networks was seen as being very important in their feeling that they had not changed (Woodgate, 1999b).

7.4.2.2 Meaning

It is believed that the meaning one assigns to an event, whether negative or positive affects how one responds to this event. It was found that adolescents dealt with their cancer experience through reinterpretation of the disease 3-6 months before completion of therapy. This included focussing on gains that they perceived in their lives due to the experience. Adolescents' were also found to need to view their illness not as chronic but as a disease with a definite end and to be dealt with within a specific period of time. "Normalcy" was defined by adolescent's as the extent to which they could return to 'normal' activities such as returning to school (Woodgate, 1999b).

It was however found that lengthy illness periods resulted in more negative perceptions and that these adolescents were more vulnerable to the cancer experience the longer the treatment lasted (Woodgate, 1999b).

7.4.2.3 Coping

Positive attitude, having hope for the future, mental redefinition of the experience, self-distraction, self talk, "ignoring" and hand holding have been identified as being coping strategies used by adolescents to cope with their disease. The seeking of spiritual support has not been frequently reported, but is seen to be important to adolescent coping. The need to find meaning in the cancer experience is evident here once again (Woodgate, 1999b).

The differences between coping in adolescents and younger children was also studied and it was found that adolescents used more emotion management coping strategies and less problem management coping strategies when cancer related problems were addressed than younger children. There was no difference when it came to non cancer related stressors however. Adolescents were also found to use more decisional and cognitive control coping strategies than younger children and that both adolescents and younger children had the ability to recognise stressors and to deal with them using these different coping strategies where appropriate. Woodgate (1999b) however points out that different researchers use different categorical systems for coping. This makes comparison of the various studies difficult. Retrospective

accounts of how adolescents coped with stressful events were also used and this recollection may have been different than the actual situation. Another drawback in the research is that the different stages of adolescence e.g. early, middle, and late have not been studied separately. Little attention has also been given to the various stages of treatments and course of the illness. Woodgate (1999b) stresses the importance of more research aimed at the various phases of adolescence and stages of treatment if successful intervention programs are to be developed.

7.4.2.4 Social Support

Strong social support especially from the family has been identified as a strong buffer and protective factor in helping the adolescent cope with the illness. The exact mechanisms of this support have however not been identified as yet. An important predictor of post treatment adjustment is perceived family functioning. This factor has an influence on mental health, self-esteem and global competence. Future research must thus include family context in order to develop preventative programs, which promote optimal psychosocial adjustment post treatment to both the survivors and their families (Woodgate, 1999b).



Woodgate (1999b) stresses the importance for the adolescent with cancer to be treated normally by family and others. Being treated normally was found to allow the adolescent to feel accepted by their social support network. Another important factor which improved perceived self-esteem is parents' belief in respect to their children's future accomplishments. When the parent has high expectations for future achievements, the child's self-esteem increases.

Most adolescents with cancer report that their parents remain the most important influence and support during treatment (Woodgate, 1999b).

7.4.2.5 External support

Support from peers has been shown to be important to the adolescent with cancer. A change in relationships with friends and peers has however been reported by adolescent cancer survivors. Adolescents with cancer may also have smaller social networks; this may however be due to treatment restraints. Support from other peers diagnosed with cancer has furthermore been found to be valuable not only during treatment, but also long into survivorship (Woodgate, 1999b).

7.4.2.6 Adjustment vs. Maladjustment

The majority of research focussing on how adolescents' adjust to the cancer experience has been aimed at identifying maladaptation and the identification of psychological problems or psychiatric disorders. It is important to note that although adolescents with cancer may be at greater risk for developing psychological problems, the diagnosis of cancer does not guarantee that psychological problems will definitely occur (Woodgate, 1999b).

The delay or difficulty in negotiating the important developmental tasks for identity development has been identified as being more of a vulnerability factor, which may predispose the adolescent to later psychological adjustment problems than an indication of psychopathology in the adolescent with cancer (Woodgate, 1999b).

Factors directly related to the physical aspects of treatment such as physical disability and side effects have been found to make the adolescent more vulnerable to stressors than aspects such as perceived self-esteem, self-confidence and self-image than healthy peers. The relative contribution of these physical aspects to the overall outcome of the cancer experience and their relationship to other variables still has to be established however (Woodgate, 1999b).

Timing of life events such as divorce of parents in relation to the cancer experience could also have a great impact upon how the adolescent is affected by the cancer experience (Woodgate, 1999b).

Personal gains and positive outcomes have recently become fields of interest in adolescent cancer research. Adolescents with cancer have reported outcomes such as increased maturity, gaining self-confidence, stronger character and growing closer to their families. The factors involved in attaining these outcomes need to be studied in more detail. Negative outcomes such as negative alterations in self-concept were also reported. It was concluded that alterations in perception could be positive or negative depending on the meaning ascribed to the cancer (Woodgate, 1999b).

7.5 Studying resilience

Woodgate (1999a & 1999b) suggests that research pertaining to resiliency in adolescent cancer patients is still in its infancy especially with regard to understanding the interacting mechanisms involved in the resiliency process. To date research in this field has revealed that adolescents can adapt to their cancer experience, protective factors which help modify adolescents' responses to cancer involve both individual and environmental factors and vulnerability factors occur mostly from the physical outcomes of cancer.

Woodgate (1999b) posits that the construct of resilience should be directly studied in the field of adolescent cancer. Data collection methods used to evaluate resilience should reflect the researchers definition of resilience. The mechanisms related to factors contributing to resilience need to be identified. There is furthermore a need to focus on developmental and situational mechanisms in protective and vulnerability processes, not just a search for broadly defined factors.

Woodgate (1999b) suggests that it might be helpful to adopt a circular, interactive model of resilience in order to understand the phenomenon better. "Recognition of the inter relatedness and individual nature of variables salient to the resilience process will allow for the implementation and evaluation of intervention programs that will break the link between stressors and adverse outcome." (Woodgate, 1999b, p.86).

Woodgate (1999a) stresses the importance of researching both resilient adolescents and those who have problems. In so doing interventions, which can increase, resilience may be developed and studied. She points out that the model provides a visual guide to the components associated with resilience and can lead practitioners to a better understanding of the construct of resilience. The development of misconceptions, which hinder the care of adolescent cancer patients, can also be eradicated. Appropriate Intervention programs for adolescent cancer patients and their families can be developed. Such programs would help promote resilience in both the adolescents and their families.

8. Conclusions and recommendations

Each year 337 patients on average are diagnosed with primary Bone Sarcomas in South Africa. Of these Osteosarcomas and Ewing Sarcomas make up about 50%. This type of tumour represents 17% of all cancers diagnosed in adolescence. This is only surpassed by the Leukemia and lymphoma group of cancers, which make up the majority of cancer in adolescence. The survival rate for Bone sarcomas has increased from 20% in the 1970s to between 65-75% the 1990s (Lindeque, McLoughlin, Dreyer & Davel, 1998; Sitas, Madhov & Wessie, 1995). The overall time of active treatment ranges from one to two years, with follow-up for the rest of their lives due to the orthopedic surgery interventions.

The median age of patients presenting with Ewing and Osteosarcomas as reported internationally as well as in South Africa is 16. The vast majority of these patients are thus in their adolescent years when they are faced with this life threatening and often disfiguring disease (Lindeque, et al., 1998).

Following an extensive literature search it became clear that most of the international literature explores psychosocial issues regarding childhood or paediatric cancer at length, but that those

issues pertaining to adolescent cancer are largely neglected. After examining the South African literature it furthermore became clear that there is no formal psychosocial intervention program available to adolescent cancer patients in South Africa at present. This includes that group of adolescent cancer patients presenting with Bone Sarcomas. As has been alluded to in this mini dissertation it seems that this group presents with unique challenges due to the integrated surgical and oncological treatment, which they undergo. The limited amount of relevant literature pertaining to psychosocial adaptation of child and adolescent cancer patients in South Africa also became apparent. It furthermore became apparent that it is advisable that the child and adolescent patient should not be investigated together in single research studies as age difference and developmental phase of both patient and family seem crucial to the accurate outcomes of such studies.

The writer would postulate that a multidisciplinary support program, incorporating adequate information regarding the specific cancer such as Bone Sarcoma and its treatments (psycho education), preparation for all treatment modalities, and the addressing of social adjustment as well as psychological adjustment issues such as the development of ASD and PTSD is crucial to the holistic care of the patient diagnosed with a cancer at any age. Such a program should be available to the patient and his/her family from diagnosis onwards and should incorporate psychosocial needs as they arise during the various transitional phases in the patient's lives e.g. from adolescent to young adult and from the school environment to tertiary education and/or work environments. The patient's psychosocial needs in the various disease phases such as diagnosis, treatment, remission, survival and terminal phases also need to be addressed in such a program.

Evidence is further mounting that psychosocial interventions improve quality of life in cancer patients to a great degree. The implementation of a psychosocial intervention program in which the patient and his/her family can receive ongoing counseling in all the treatment phases as well as centres is advisable in this regard. The above points are supported in the following publications: Connerly, 2001; Coulter, 1998; Fallowfield, 1995; Foley, 1993; Hildebrand & Annala, 1998;

Kameny & Bearison, 1999; Kisker, Fethke & Tarnous, 1997; Lee, Fung, Wu, Lau-Yu, & Lieh-Mak, 1998; Maggiolini et al., 2000; Walker, Heys & Eremin 1999.

Furthermore the fostering of resilience should be central in the design of any such program as well as the investigation of psychosocial concerns and adjustment in adolescent cancer patients. It is however important to recognize the inherent resilience in many adolescent cancer patients. This resilience can be utilized very effectively in any individualized psychosocial support program.

The writer concurs with Roberts, et al. (1997,p2) when they point out: "Cancer treatments create life changes that disrupt the normal psychological and social developmental tasks..." of these young people. Research shows that this age group - adolescent to young adult - has little in common with older patients and small children and has unique concerns ranging from mortality issues to worries about future employment as well as infertility (Roberts, et al., 1997). Yet the risk for these patients to 'fall through the cracks' as far as psychosocial care is concerned is large. They are usually either being treated in an adult setting or a pediatric setting and the specific psychosocial and developmental needs of the adolescent may be neglected (Edwards, 2001; Foley, 1993; Kameny & Bearison, 1999; Kisker et al., 1997; Lewis, 1996; Schwartz, Feinberg et al., 1999).

This is a group of patients who seem to have been psychosocially neglected in South Africa. Meticulous and relevant research in the field of adolescent psycho oncology is thus needed in order to be able to adequately ascertain the psychosocial needs of this group of patients. Only then can an effective psychosocial support program aimed at their specific needs be devised. Such a program can then be implemented in order to redress the shortcomings in the psychosocial care of adolescent cancer patients suffering from the specific types of cancer such as Bone Sarcoma, which is so prevalent in this age group.

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