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Art therapy in the paediatric oncology setting: An assessment of the feasibility of art therapy to address the psychosocial needs of paediatric cancer patients

Anthea Carboni
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ART THERAPY IN THE PAEDIATRIC ONCOLOGY SETTING:

**An assessment of the feasibility of art therapy
to address the psychosocial needs of paediatric
cancer patients**

**by
Anthea Carboni
BA. Dip.Ed.**

A thesis submitted in partial fulfilment of the requirements

for the award of Master of Arts (Art Therapy)

**Academy of Performing Arts
School of Visual Arts
Edith Cowan University**

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USE OF THESIS

The Use of Thesis statement is not included in this version of the thesis.

Abstract

It is well recognised that children with cancer have special needs. Art therapy has been shown to be effective in meeting some of these needs. An exploratory study was conducted to assess the feasibility of art therapy to address the psychosocial needs of paediatric cancer patients in a medical setting where art therapy has not been practised before. A qualitative research design was used to investigate the research questions, using interviews as the main instrument. Subjects were recruited from the oncology team of a metropolitan children's hospital. The sample of thirteen informants consisted of representatives from the medical, nursing and allied health professions (occupational therapy, social work, teaching, chaplaincy, dietetics and physiotherapy). Interviews were conducted with the aim of obtaining background information on the area under investigation (the illness, the patient, staff roles and psychosocial services), as well as informants' perceptions about working in the oncology setting, the psychosocial needs of paediatric cancer patients, the extent to which these needs are met, the role of art and the potential role of art therapy. The responses of informants indicate that the experience of cancer is a highly stressful one for both the child and the family and that both the child and family require ongoing psychosocial intervention to help them cope with the overall experience of illness. Informants' perceptions of how the child and family cope with the experience of cancer and the extent to which psychosocial services are effective in addressing the needs of paediatric cancer patients and the family were seen to vary dramatically within the sample group. Based on the data, it

would appear that the psychosocial needs of the patient and the family are not adequately met and that the extent to which psychosocial services are effective in meeting these needs is dependent on several interrelating factors. The use of art in paediatric oncology was perceived by most informants as appropriate in helping to meet the psychosocial needs of patients and more than half (9 out of 13) of the informants expressed a belief in the value of art as a therapeutic intervention in paediatric oncology. Perceptions of the use of art therapy in paediatric oncology were influenced by the level of informants' understanding and experience of, as well as concerns for the practice of art therapy in this setting. Six out of thirteen informants expressed an interest in seeing art therapy integrated into the paediatric oncology setting. A conclusion as to the feasibility of art therapy in the paediatric oncology setting was reached, on the basis of both the research data and the literature on the use of art therapy with physically ill children. The findings of the research indicate that art therapy in the paediatric oncology setting would be a valuable addition to existing psychosocial services and a recommendation for the introduction of a programme in art therapy is suggested.

Declaration

I certify that this thesis does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any institution of higher education; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

Signed

Date

14 February 1996

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Chapter 1: Introduction

Background of the study

The idea for this research began while I was on placement in the psychiatry department at the hospital where the research was conducted. In talking with my supervisor, a consultant psychiatrist at the hospital, the idea of looking at other areas in the hospital where art therapy would be beneficial was suggested. My interest was due in part to my experience as an art therapy student in a setting which did not seem particularly open to new and alternative approaches to the treatment of patients (child and adolescent psychiatry). I was curious to know what staff in other areas of the hospital thought about art therapy and whether or not they were open to the idea of exploring the role of art therapy in addressing the psychosocial needs of their patients. I approached several departments, including oncology, respiratory medicine and the renal unit, and in all cases the doctors spoken to indicated an interest in the idea and support for the conduct of the research. A decision was made to restrict the focus of the research to investigating the role of art therapy in oncology, rather than attempting to explore several areas, each with its own specific issues and concerns. I chose oncology on the basis of the availability of literature on art therapy and paediatric oncology as well as on the level of interest and openness expressed by the head of the oncology department towards the research project.

Purpose of research

The broad aim of the research was to explore the role of art therapy in the medical setting, leading to an increased understanding of the issues involved in implementing art therapy. The specific research objective was to assess the feasibility of art therapy in paediatric oncology. Preparatory reading covered two main areas, namely, the impact of cancer on the child and how children cope with the experience of cancer, as well as the use of art therapy in addressing the psychosocial needs of paediatric cancer patients. Literature on the first area stressed the importance of psychosocial support and art therapy literature indicated the effectiveness of art therapy as a psychosocial intervention.

Statement of the problem

Much of the literature on childhood cancer addresses the issue of the psychological impact of cancer on the child and family and the need to address the problems which often occur as a result (eg. Katz & Jay, 1984; Kazak & Nachman, 1991; Mulhern & Friedman, 1990; Tovian, 1991). Literature on the use of art therapy in the paediatric oncology setting points to the use of art therapy as an effective means of addressing the social, emotional and psychological needs of children diagnosed with cancer, and as a valuable addition to psychosocial treatment services (eg. Cotton, 1985; Councill, 1993; Sourkes, 1991; Walker, 1989). The following research questions were formulated in an attempt to assess the potential role of art therapy in a medical setting where art therapy is not currently practised:

- i) How do staff involved in the treatment of paediatric cancer patients perceive the usefulness of art therapy in addressing the psychosocial needs of this population?
- ii) How feasible is art therapy as a psychosocial service in the paediatric oncology setting?

Rationale

Art therapy can enrich the overall clinical treatment of paediatric cancer patients by providing a unique form of communication and expression that allows for a symbolic representation of children's subjective experiences of being ill. Art therapy is an effective means of attending to the social, emotional and psychological needs of children with cancer, contributing to their overall quality of life. It is a non-threatening way of providing the child with an opportunity to interact with staff and others on the child's terms. It provides opportunities for the child to address specific areas of difficulty such as adjustment to hospitalisation, anxiety and fear surrounding medical treatment and the psychological impact of and adjustment to the illness. Participation in art therapy is a way of giving children a voice, in that they are assisted to explore and express their experiences and related emotions. This in turn enables the child to gain a sense of containment and control by understanding and assimilating what is happening to him or her. The art therapy process is designed to provide support and comfort through the exploration of thoughts and feelings in visual form.

Since art therapy is a relatively new profession, with no art therapists currently practising in any Perth metropolitan hospital, a research study

based on exploring the perceptions of art therapy in the medical setting was warranted. Art therapy research in the medical setting offers potential benefits to both the researcher and to those who work in this setting. The researcher has contact with professionals in related disciplines who, as experts in their field, are able to provide specialised knowledge relevant to the subject of the research. In turn, the researcher is able to provide specialised knowledge of art therapy and its potential for addressing the psychosocial needs of children who are physically ill.

Chapter 2: Review of the Literature

The psychosocial impact of childhood cancer

Childhood cancer, once considered a terminal illness, is now defined as a chronic illness, due to increased rates of survival and greater possibilities for cure for particular illnesses (Kazak & Nachman, 1991). As a result, cancer has become a more ambiguous experience for the child and family, since, despite increased survival rates, "all families must face the threat of possible death" (p.464). Living with cancer implies constant uncertainty given that "there can be no assurance of cure" (Brown, 1989, p.247). Once a diagnosis of cancer has been made, many outcomes are possible: remission, cure and long-term survival; relapse; recurrent tumour; metastasis; death from complications of treatment; and death as a result of refusing to comply with treatment (p.248). The changes and distress brought on by a diagnosis of cancer and the treatment which follows have an impact on the overall quality of life, according to psychologist Steven Tovian (1991). Becoming a cancer patient means facing the possibility of a disabling illness; altered goals, roles and plans; separation from the family; alienation from friends and peers; loss of or change in physical functioning; and death (Tovian, 1991, p.332). Mulhern and Freidman (1990), in a discussion of the psychological issues associated with the treatment of childhood leukaemia, outline some of the issues facing the child and family as a result of a diagnosis of cancer in the child. The family faces uncertainty about the course of the illness and the prospects for cure, prolonged treatment, extended hospitalisations, and disruptions to family functioning. In the course of treatment, the child experiences

multiple painful medical procedures, aversive side effects of treatment, alterations in appearance and disruption of age-appropriate activities (p.270). It is widely reported that children with cancer are at risk for the development of both acute and chronic psychological problems in relation to diagnosis and treatment. Acute problems, according to Mulhern and Freidman, include adjustment to diagnosis, side effects of treatment, and painful medical procedures (p.270). Chronic problems which children may experience include a decline in learning abilities, school failure and personal and social maladjustment (p.284). The development of psychological problems in relation to childhood cancer, according to Tovian (1991), is determined by "the unique interactions of the cancer, its treatment, and by pre-morbid demographic and social features", such as the age and sex of the child, family functioning and the child's inherent coping resources (p.332). Preschool children may experience problems in relation to limited interaction with other children, a lack of understanding about the disease and by feelings of guilt. School-age children and adolescents can be adversely affected by diminished social interaction and alienation from peers, learning disabilities, school absences and parental over-protectiveness. Adolescents may experience problems in relation to anxiety and uncertainty about the future and negative risk-taking behaviour (p.334).

A range of emotional and behavioural reactions can occur as a reaction to the diagnosis and treatment of cancer. Such reactions include shock, disbelief, denial, anxiety, hostility and depression (Tovian, 1991, p.333). Fears of death and separation are frequently associated with diagnosis (Kaufman, Harbeck, Olsen & Nitschke, 1992) and children undergoing

treatment for cancer often suffer from regression, loss of self-esteem (Brunquell & Hall, 1983), depression and generalised anxiety (Kazak & Nachman, 1991). Depression and anxiety may be denied however, as the child uses denial as a coping mechanism in order to maintain a sense of control (Kazak & Nachman, 1991). Behavioural reactions such as non-compliance with treatment can occur as a reaction to the stress of being ill (Katz & Jay, 1984; Kaufman et al., 1992). Treatment non-adherence is a common form of resistance in childhood cancer and also represents a way of taking control of the illness (Taylor, 1991, p. 614).

Psychosocial intervention for children with cancer

With increased survival rates in childhood cancer, the focus of psychosocial intervention has shifted from the management of death as the primary concern to the management of uncertainty, adherence to treatment and behaviour problems (Taylor, 1991, p. 620). Most oncology centres, according to Mulhern and Freidman (1990), recognise the importance of early intervention, the provision of psychosocial support throughout treatment, normalisation of family functioning and continuation of age-appropriate activities of the child (p. 289). The goal of psychosocial intervention in oncology is to enable the patient to function physically, socially and emotionally at the highest level possible within the constraints of the disease (Tovian, 1991, p. 338). Interventions in paediatric oncology are aimed at helping the child to strengthen defences, enhance coping skills and to reduce fears of isolation (Wellisch, 1981 in Tovian, 1991, p. 339). Koocher (1985) identified specific points of emotional vulnerability in childhood cancer at which intervention is

appropriate: receiving the diagnosis; at the outset of treatment; aversive side-effects of treatment; reaching the end of a treatment phase; re-entry into school, family and social life; recurrence or relapse; terminal phase; and anniversary or life-marker events for the survivor (Tovian, 1991, p. 333). Whitt (1984), citing extensive research in psychosocial adaptation and intervention in chronic childhood illness, suggests a variety of approaches which "may lessen the stress and uncertainty [of the illness] for the child" (p.92). Preparation for hospital admission, medical and surgical procedures; repeated discussion of illness phenomena and treatment regimes; opportunities for participation in normal activities; behavioural therapies, relaxation, hypnosis, guided fantasy and biofeedback; and psychotherapy can all help in pain management and in fostering a sense of control. Opportunities for supportive interactions with other children with a similar physical condition and liaison with teachers and others involved in the child's reentry into the community and school are also listed as "having a place in the comprehensive care of the chronically ill child" (p.92).

Terminal illness

Despite increased survival rates in childhood cancer, a proportion of children will at some stage of the illness be diagnosed as terminally ill. The impact of a diagnosis of terminal illness is experienced by the child at physical, emotional and spiritual levels. Throughout the course of the illness, the child may physically experience weakness, nausea and vomiting, lack of appetite and weight loss, a decrease in activity level, irritability and general fatigue. Emotionally, the child may have flattened

affect, low self-esteem, increased psychological dependence on others and a tendency to withdrawal and isolation (Mitchell Hodges, 1981). Common concerns of children who are faced with a life-threatening illness include fear of abandonment or separation from the family; feelings of being punished; dependency; mutilation; death; body-image concerns (Gray, 1989); isolation; and fear of the unknown (Schmitt & Guzzino, 1985). Terminally ill children can exhibit many psychological responses to illness, such as acting out, depression, fear and withdrawal (Blom, 1958 in Schmitt & Guzzino, 1985). Depression may result from both the physical pain of the illness and treatment procedures, as well as in relation to the many losses caused by the illness. Withdrawal, internalisation of feelings and decreased communication can lead to a sense of increased isolation for the terminally ill child. Lack of spontaneity, apathy and despair may result from a sense of helplessness in being able to change their situation (Schmitt & Guzzino, 1985, p. 161). These responses, according to expressive therapists Schmitt and Guzzino, are largely the result of the child's grief over the losses caused by the illness, such as loss of well-being, ability, control, physical integrity, independence, and inevitably, loss of life.

Children's perceptions and understanding of death are closely related to their stages of emotional and cognitive development, according to psychiatrists Kaplan and Saddock (1991, p. 58) and other professionals who work with terminally ill children. Before the age of five, children have limited understanding of death, which is seen as a temporary separation (Mitchell Hodges, 1981). Concerns of children at this stage are related to feelings that parents will be missed (Gray, 1989). Between the

ages of five and ten, children have a sense of inevitable mortality (Kaplan & Saddock, 1991, p. 58), although they do not necessarily apply it to themselves (Mitchell Hodges, 1980). Their concerns may relate to a fear of pain and of dying alone, as well as what they will miss out on in the future (Gray, 1989). Around the age of ten, children are aware that death is something that can happen to both children and adults (Kaplan & Saddock, 1991, p. 58). There is a strong reaction in children of this age to the death of others as well as when confronted with their own death (Mitchell Hodges, 1981). At puberty, adolescents understand that death is "irreversible, universal and inevitable" (Kaplan & Saddock, 1991, p. 58). Adolescents are faced with the realisation that there will be no future (Gray, 1989), however concerns may initially relate more to issues of body image and control of the environment than to the inevitable loss of life (Kaplan & Saddock, 1991, p. 58).

Psychosocial intervention for terminally ill children

Preparation, support and protection from physical and psychological pain are important in helping to meet the needs of terminally ill children, although these cannot "forestall or thwart the [child's] anxieties which occur naturally" (Barowsky, 1978 in Gray, 1989, p. 212). Open communication among terminally ill adult patients, family and staff is most often recommended by those who work in this area (Kaplan & Saddock, 1991). Most treatment centres support complete awareness of the diagnosis, treatment and prognosis and encourage the patient and family to communicate openly with one another (p.57). Open communication, according to Feifel (1973) "tends to mitigate feelings of inadequacy and

guilt, not only in the dying patient, but among the professional people involved and family members as well" (in Tate, 1989, p. 115). Psychiatrist Elizabeth Kubler-Ross (1983) suggests the same approach should be adopted with children who are terminally ill, given that "children do know what is happening" and the common stages of grieving in relation to one's own death apply to children as well as to adults. According to Kubler-Ross, children may not express awareness of their terminal condition overtly, but they are aware of their prognosis at an unconscious level. Children are "attuned to events in their lives and express this knowledge, often symbolically, to those who will hear them" (in Bertoia & Allan, 1988, p. 207). Children cope better with death when their thoughts, feelings and questions are addressed (Mitchell Hodges, 1981). Dying is made easier, according to Tate (1989), when individuals "feel understood and able to express feelings, fears and hopes" (p.115). Despite a natural curiosity which children have about death (Gray, 1989), terminally ill children may have difficulty verbalising their thoughts and feelings with regard to their own illness (Mitchell Hodges, 1981). Barriers to communication may be due to personal fears and anxieties, a limited vocabulary or a desire to protect others from "the hurt and sadness that have resulted from the illness" (p.55). Parents may avoid discussion with the child about his or her terminal condition in an attempt to shield the child from a knowledge of death (Kaplan & Saddock, 1991). Avoidance, however, may create an "air of mystery" and lead to the development of irrational fears in the child (p. 58).

The expression of conflicts and concerns by the terminally ill child is a healthy response to the illness (Schmitt & Guzzino, 1985) and it is

important that the child's feelings of sadness, anger and fear are acknowledged (Gray, 1989). Accepting the child's awareness and understanding of death, recognising the child's fears and anxieties and exploring these with the child helps the child to feel more relaxed and secure (Mitchell Hodges, 1981). If children are permitted and encouraged to confront the powerful feelings that accompany the illness, they can experience, practise and acquire alternative coping behaviours (Schmitt & Guzzino, 1985, p. 161).

Art therapy and physical illness

The practice of art therapy in the area of physical illness is a relatively new departure from the more traditional settings such as psychiatry (Skaife, 1988). In documenting the development of art therapy with physically ill patients, Skaife (1993) describes an early connection between art therapy and physical illness which is recognised as marking the beginnings of art therapy as a profession in Britain. Art therapy was first practised in a sanatorium for recovering tuberculosis patients. In 1945, an artist by the name of Adrian Hill continued painting while a patient in the sanatorium and subsequently introduced art to other patients. In Hill's view, involvement in the process of art making was therapeutic and provided patients with a diversion from "morbid introspection", prevented boredom and helped to "speed up" recovery (p.24). Art therapy developed as a profession in both England and America and despite its early connection with physical illness, it is traditionally associated with the mental health field.

Art therapy in the medical setting reflects a more recent development in the evolution of art therapy as a profession. The practice of art therapy with physically ill adults and children has developed in recognition of the psychological impact of a physical illness or disability. Medical art therapy is defined as "the specific use of art therapy with individuals who are physically ill, experiencing trauma to the body, or undergoing aggressive medical treatment such as surgery or chemotherapy" (Malchiodi, 1993, p. 66). The goal of medical art therapy is "to meet each person's needs for exploration of his or her disease experience" through the use of expressive modalities (p. 68). A background to the practice of art therapy in the medical setting is provided by art therapists Cathy Malchiodi (1993) and Sally Skaife (1993), with reference to a selection of the literature on art therapy with physically ill adult patients. Although it is apparent that there are differences in approach and purpose between individual art therapists working in a variety of settings and with a variety of patient populations (eg. multiple sclerosis, chronic pain, renal failure, cancer and Aids), there are nevertheless, commonalities underlying the practice of art therapy in this field, which can be summarised as follows:

- a. the recognition of the emotional effects of physical illness
- b. the limitations of the medical model in addressing the non-medical needs of the patient
- c. the importance of addressing the psychosocial needs of the patient
- d. the role of art therapy in addressing the psychosocial needs of the patient
- e. the place of art therapy in the medical setting.

These aspects will be discussed briefly with reference to some of the literature on the use of art therapy with chronically or seriously ill adult

patients.

a. Emotional effects of illness

Art therapist Kathleen Kern-Pilch (1980) describes the effects of physical illness and hospitalisation as requiring many psychological adjustments by the patient: "Illness and hospitalisation entail the relinquishment of activity in favour of a more passive role, with the result that the patient comes to view himself as helpless and oftentimes isolated" (p. 3). Having to face mental and physical impairments as a result of serious illness can be highly stressful (Rosner David & Sageman, 1984) and can have a negative effect on feelings of personal worth (Kern-Pilch, 1980). Hospitalised patients are faced with a series of losses, including loss of personal freedom, a sense of well-being and control of one's body (Wood, 1990). For patients who are chronically ill, the sense of loss which is experienced in relation to one's physical well-being can give rise to anger, envy and grief (Szepanski, 1988). When the chronic illness is fatal, there is an added difficulty of facing death when the patient has "not lived life to the full" (p.10). Patients diagnosed with a terminal illness can experience depression and social isolation (Rosner David & Sageman, 1984) and may, as a result, feel overwhelmed and defeated (Wood, 1990). Typical issues of patients dying of Aids, for example, are feelings of worthlessness, rejection and fears engendered by increasing helplessness and dependency on others (Rosner David & Sageman, 1984).

b. Limitations of the medical model

The emotional effects of illness and the "immense changes to the self" that result from chronic illness are, according to Skaife (1988), something

which western medicine "appears to take little account of" (p.3). The primary concern in medical settings is necessarily the physical care of patients. Although psychological dimensions of treatment are recognised as being important, "the first goal is to expediently treat the presenting illness or condition" (Malchiodi, 1993, p. 66). The medical approach of "splitting off the sick part" may be appropriate when an illness can be treated but not, according to Skaife (1993), when the patient needs to come to terms with his or her altered state, as is the case for chronically and seriously ill patients. Medical staff may not fully understand psychological issues which affect their patients and they may not be aware of any problems a patient is having with accepting or adjusting to hospitalisation or illness (Kern-Pilch, 1980). Szepanski (1988) suggests however, that "it is misguided to think that because a person's physical needs are met that this is enough" (p.10).

c. The importance of meeting psychosocial needs

Physically ill patients have a need to express, communicate and work through their feelings about being ill (Skaife, 1988). The inclusion of a therapeutic process within the medical setting provides the patient with the opportunity to address "the many and complex issues involved with a physical, emotional and spiritual amelioration" (Bussard, Peck & Eaton, 1989, p. 112). Meeting the psychosocial needs of patients can be achieved more effectively when therapeutic services are designed with this purpose in mind. Kern-Pilch (1980) cites a definition of liaison psychiatry (Strain and Grossman, 1975), as a model for psychosocial intervention in the medical setting and on which art therapy programmes could be based. Liaison psychiatry stresses the recognition and expression of feelings

related to illness and hospitalisation; encourages social interaction and the formation of supportive relationships; provides appropriate mechanisms for the handling of stress; and coordinates lay and professional understanding of the patient's reaction to illness and hospitalisation (p.3).

d. The role of art therapy in addressing the psychosocial needs of patients

Art therapy in the medical setting addresses the psychosocial needs of physically ill patients on several levels. According to art therapist Camilla Connell (1992), art therapy encourages the release of powerful feelings in relation to serious illness; provides a diversion and enhances coping; allows for a reassessment of priorities and goals; and provides a means of gaining support and communicating with others. In using art therapy to help seriously or terminally ill patients to face issues surrounding their own death, art therapists "consistently observe the power and potential of art to help identify, cope with and heal the pain associated with inevitable loss of life" (Malchiodi, 1992, p.114). The process of creating images in art therapy offers a means of exploring and questioning what is happening at all levels - physically, emotionally and spiritually (Connell, 1992). Art therapy by-passes verbal defences and enables a more direct connection with feelings about being ill. Issues are made conscious and external rather than remaining suppressed (Wood, 1990). The discharge of powerful feelings which often occurs in art therapy is, according to Szepanski (1988), essential to the patient's general well-being. Art can serve as an outlet for energies that might otherwise find expression in more negative ways (Kern-Pilch, 1980) and provides a safe environment which allows for the expression of strong feeling (Szepanski, 1988). Art

making can be diversional, providing an alternative focus which is actively pursued by the patient. In creating art, the patient moves from a passive role to an active, productive one (Rosner David & Sageman, 1984; Kern-Pilch, 1980). Involvement in art making reinforces the patient's ability to act for himself (Wood, 1990). Making art involves making decisions, asserting oneself and maintaining control (Kern-Pilch, 1980). Through the production of "personally expressive art works" the patient can experience a level of satisfaction and accomplishment which leads to increased self-esteem (p.3). In the process of creating images the patient is provided with opportunities to reassess priorities and goals. Artwork can help the patient to resolve feelings about illness and death, it can prompt a life review and it can be used to settle unfinished business (Kern-Pilch, 1980). As a means of gaining support , or in communicating with others, artwork can provide a point of contact with other patients, family and staff (Kern-Pilch , 1980), helping the patient to feel less isolated and more confident in his or her ability to cope with the illness (Rosner David & Sageman, 1984). For the family and staff, art offers a new perspective from which to see and understand the patient. Drawings reveal facets of the patient's personality which might never have surfaced otherwise (Shapiro, 1985). When the patient's concerns are revealed in art and shared with others, the patient's situation is greatly enlightened (Connell, 1992). The image itself may have special significance for the surviving family and friends of a terminally ill patient, who "lives on" through the artwork, helping to "counter the despair of the separation of death" (Wood, 1990, p. 32).

e. The place of art therapy in the medical setting

Art therapy in the medical setting is fundamentally different from the more traditional practice of art therapy, in that art interventions need to be designed with the overall medical treatment of the patient in mind and with a knowledge of the particular illness, medications or procedures involved in each individual case (Malchiodi, 1993). Many art therapists working in the hospital setting, according to art therapist Paula Jeppson (1982), have been able to demonstrate that art therapy can help meet the psychosocial needs of patients and families going through a medical crisis. Many patients "want and need these services" and many health professionals find art therapy services invaluable, seeing them as an attempt to "humanise the institution" (p. 47). Art therapy in the medical setting has a "valuable and irreplaceable" part to play in meeting the needs of patients through different stages of their illness (Connell, 1992). The use of art expression within a total medical treatment programme may be one of the most viable avenues for enabling patients to find emotional and spiritual healing in their lives (Malchiodi, 1993).

Art therapy with physically ill children

Art therapy with physically ill children in the medical setting provides the child with a means for relating concerns about the illness, the experience of hospitalisation and separation from home (Landgarten, 1981, pp. 121-122). Children use art as a way of expressing their feelings about themselves and their world (Rae, 1991). Any physical harm or injury affects the way children understand themselves, creating anxiety and uncertainty (Schwarz, 1978). Children who suffer from either

temporary physical disturbance or chronic illness, according to Schwarz, readily involve themselves in art-making as a means of expressing their predicaments. The difficulty which children experience in expressing their feelings verbally (Case & Dalley, 1990) may be even greater when they are ill and in an unfamiliar environment such as hospital (Rae, 1991). Children's artwork communicates their affective state far better than words, according to Rae, who suggests that hospitalised children may be more comfortable talking about their feelings in relation to the artwork. This notion is supported by Rollins (1990) in a statement about the artwork of hospitalised children as providing "a much more accurate description of how the child really feels, what he or she is concerned about and why" (p. 81). Common themes which appear in the artwork of physically ill and hospitalised children are: fear of separation and hospitalisation; anxiety over medical procedures; generalised anxiety, sadness and withdrawal; and developmental regression (Rae, 1991). Themes relating to the child's self-image or body-image are also frequently present in the artwork (Oppenheim Cameron, Juszczak & Wallace, 1984; Schwarz, 1978).

The use of art with hospitalised children is recommended by many health care professionals (eg. Parish, 1986; Radziewicz & Schneider, 1992; Rollins, 1990; Romero, 1986). The use of non-verbal methods of expression are encouraged as a way of enhancing the child's active participation and the playing out of his or her experience (Romero, 1986). Art materials present optimum opportunities for the expression and communication of feelings about illness and hospitalisation, according to Rollins (1990). Rollins describes several ways in which involvement in art is beneficial

for the child: providing opportunities for making choices, feeling in control and to do something normal and familiar; as a means of communication; offering a non-threatening outlet for venting feelings; increasing self-esteem and a sense of mastery; developing creative potential; and stimulation of imagination. Art can play a substantial role in minimising or eliminating the negative effects of hospitalisation, helping the child to cope with the stress of illness and hospitalisation (Rollins, 1990; Romero, 1986). School-age children, according to Romero, rely on fantasy as a way of dealing with anxiety, resolving conflict and completing their understanding of reality. The projection of the child's thoughts, feelings, conflicts and needs through art can help the child to gain control, achieve mastery and reduce anxiety and stress. Children's expressions in play, fantasy and art can help others understand how they are interpreting the experience of illness and hospitalisation. These expressions give clues to the child's personality and coping skills (Romero, 1986), providing insight into the child's unique needs and perception of events (Parish, 1986). Health care professionals will often learn more about a child's or adolescent's feelings, thoughts and coping skills, according to Parish, by using less conventional, non-verbal communication methods.

Art therapists working with physically ill and hospitalised children have used art to facilitate the expression of feelings, providing opportunities to master anxiety, stress and fear in response to experiences such as hospitalisation, surgical procedures, medical treatment and changes in physical appearance (Crowl, 1980; DiCowden, 1987; Epping & Willmuth, 1994; Geraghty, 1985; Oppenheim Cameron et al., 1984). Art therapist

Barbara Geraghty (1985) presents a case study using art therapy to provide a hospitalised child with an outlet for the expression of negative feelings associated with hospitalisation and separation from the family. The use of drawing enabled the child to express feelings that were "too frightening for her to say out loud" (p. 127), providing a safe vehicle for communicating with the therapist. Art therapy, according to Geraghty, afforded the child a sense of control, which was badly needed at a time when she was "exposed to frightening or painful experiences beyond her control" (p. 128). The use of art therapy in preparing a child for surgery is described by art therapist Marianne Crowl (1980). Art allowed for the expression of feelings about a forthcoming operation when "it was evident that [the child] needed to express his inner anxiety but could not do so in words"(p.49). The expression of the child's feelings, together with the therapist's encouraging response, helped to allay the child's fears and the threat of the unknown, enabling the child to master his feelings of anxiety.

Art therapy in paediatric rehabilitation addresses the emotional and rehabilitation needs of patients hospitalised for brief periods as well as for long-term management of disability or physical illness (DiCowden, 1987). Art therapy provides opportunities to deal with issues such as changes in appearance and the impact of body-image and self-esteem, helping patients to adjust to permanent disability and to achieve mastery of normal developmental tasks. The child's "heightened sense of vulnerability and powerlessness" which is experienced as a result of illness and hospitalisation, is often revealed in drawings (Oppenheim Cameron et al., 1984, p.108). The expression of concerns in the artwork can

provide a basis for discussion with the child about such fears as mutilation and body change, or areas of difficulty such as feeling overwhelmed, frightened and helpless. Once the frightening image or thought is drawn, according to DiCowden (1987), it can be viewed, discussed and dealt with at a more comfortable and safe distance. Epping and Willmuth (1994) describe the use of art therapy in the rehabilitation of adolescents with spinal cord injury. Art therapy is an "effective alternative means of self-expression that serves as a catalyst for adjustment" (p. 79), enabling an indirect exploration of issues relating to self-concept, body-image and relationship to others. Adolescent patients frequently exhibit denial and are typically difficult to engage in verbal psychotherapy, according to these authors. The use of art therapy provides adolescents with a means to distance themselves from potentially difficult feelings while allowing for an exploration of their unspoken concerns. Through such exploration, Epping and Willmuth maintain, adolescents may experience renewed mastery, greater self-acceptance and a sense of hopefulness in regard to their future.

Art therapy with terminally ill children

Children confronting death, according to expressive therapist's Schmitt and Guzzino (1985), are "children in crisis" (p.155). The impact of death, dying and bereavement, is such that "often what emerges [as a response] is beyond our cognitive grasp and difficult to articulate" (Corr & Corr, 1985, p. 153). The use of art therapy with terminally ill children is valuable because art allows for a symbolic release of some of the powerful emotions connected with serious illness and dying (Bertoia & Allan,

1988). The use of art therapy, a primarily non-cognitive mode of communication, is therefore an "essential consideration" in chronic illness, terminal illness and bereavement (Corr & Corr, 1985, p. 153).

Involvement in art therapy can enhance the terminally ill child's ability to cope with the illness (Schmitt & Guzzino, 1985). Expression in art allows emotional energy to be channelled rather than expended in a dysfunctional or unproductive manner. Given the opportunity for symbolic release through self-expression in art, there is less risk of the child hiding or denying his or her feelings, or of becoming fearful and withdrawn. Although children often find it difficult to talk about their fears, according to Bertoia and Allan (1988), they will portray them quite visibly in drawings. Children who are aware of their impending death may express little overt emotion at a verbal level but much may appear in symbolic form or in unusual behaviours. Involvement in art therapy for terminally ill children provides them with opportunities for participation and interaction (Mitchell Hodges, 1981), helping to alleviate some of the loneliness and isolation which can be experienced (Bertoia & Allan, 1988). Communication with others is enhanced via the production and discussion of artwork, providing staff and the family with insights into the inner-world issues of the child. The development of a supportive relationship which art therapy allows (Mitchell Hodges, 1981) provides a means for the child of working through the conflict of being "bereft of life" (Simon, 1981, p. 135).

Case examples from the literature on art therapy with terminally ill children illustrate how art therapy has been used to address some of the

issues identified above. Parish (1986) describes the use of art to enable the expression of repressed emotion. The description of the therapeutic process - from reading a child a story about clowns who hide their feelings, to the making of a mask and the subsequent expression of "intense fear and horror" which was depicted by the child on the mask - vividly illustrates the use of art as a process of symbolic interaction (Corr & Corr, 1985) and which is often a far more effective means of communication than verbal interaction alone. Mitchell Hodges (1981) describes a terminally ill child's spontaneous drawing of a monster and the discussion with the art therapist in which the child verbalised feelings of being punished, a common reaction of children who are physically ill. Another child drew an image of a cemetery, using the image to verbalise her fears of dying to the therapist. Drawing and talking about fearful thoughts and images, according to Schmitt and Guzzino (1985), enables the child to gain control over the fear. When a child is encouraged to talk directly to a monster drawn in an image, the child is helped to take control by telling it to "leave me alone!" (p.162). Involving terminally ill children in art, these authors maintain, enables the art therapist and others to identify issues such as the child's level of anxiety, fear and lack of control, providing insight into the child's needs and requirements for support.

Art therapy with paediatric cancer patients

Art therapy in the paediatric oncology setting addresses the emotional and developmental needs of an "essentially normal population under extreme stress" (Councill, 1993, p. 78). The threat to the child's sense of

security which the diagnosis and treatment of cancer poses, means that children have a need to assimilate the experience, whereby the threatening elements can be contained and controlled (Sourkes, 1991). Children with cancer, according to psychologist Barbara Sourkes, need opportunities, encouragement and support to express themselves emotionally and to explore areas of conflict. Art therapy is a "powerful tool" which facilitates the expression and working through of the conflict of such a complex experience (p. 82). Walker (1989) recommends the use of both play and art therapy in paediatric oncology for children who are experiencing "a significant amount of emotional stress" (p. 121). Involvement in play and art provides opportunities for the release of tension through the expression of emotion and helps the child to make sense of such experiences as separation from parents, treatments and procedures and isolation. Art and play can provide links to the real world or they may offer a temporary escape or diversion which can facilitate the child's adaptation to illness and hospitalisation. Walker suggests that children be actively encouraged to engage in a therapeutic relationship using art and play, encouraging the child's emotional expression and exploration of areas of conflict, as well as increasing the awareness for others of the child's needs and level of understanding of the illness experience.

Sourkes (1991) outlines a structured approach using art therapy with paediatric cancer patients and their siblings which allows the child to focus on specific topics, such as emotional responses to being diagnosed with cancer. The child is encouraged both to explore his or her concerns relating to the illness experience in visual form and to provide a verbal

explanation of the image which is, Sourkes maintains, based within the child's "psychic reality" (p. 84). This approach recognises and values the individual child's reactions to commonly experienced areas of difficulty for all children diagnosed with cancer, such as medical procedures, isolation and concerns about death. Cotton (1985) presents a case study describing the use of art therapy with a terminally ill leukaemic child and the potential for psychological healing inherent in the process of creating images. Art therapy, according to art therapist Margaret Cotton, provided the child with an interest and an incentive to reveal her feelings which otherwise remained unexpressed. Cotton stresses the importance of a continuous and supportive therapeutic relationship in which the child feels safe enough to allow for the emergence of emotion in pictorial expression. Art experiences, Cotton surmises, are valuable for terminally ill children in their potential for helping to alleviate the mental and physical trauma of the disease through the expression and release of underlying feelings in visual form.

One of the most comprehensive discussions on the use of art therapy with paediatric cancer patients is by art therapist Tracy Council (1993). Council outlines a hospital-based art therapy programme offering psychosocial support to patients throughout different phases of their illness: diagnosis and early treatment, the middle phase of treatment and relapse and palliative care. Case studies illustrate typical issues which emerge at each stage and the use of art therapy to address these issues. Art activities are offered in the outpatients' area and are available to both inpatients and outpatients. Participation in art therapy sessions is decided upon by the child, since choice is "essential to building a therapeutic

alliance in this setting" (p. 79) and offers the child at least one area over which they have control. The artwork of paediatric cancer patients, according to Councill, commonly reflects issues and concerns noted by other authors (eg. Cotton, 1985; Gray, 1985; Rae, 1991; Schmitt & Guzzino, 1985; Sourkes, 1991) such as separation anxiety, alienation, anger and aggression, fear, body image and self-concept, beliefs about treatment and concerns about death.

The first phase (diagnosis and early treatment) is associated with issues surrounding body image, identity and self-esteem, according to Councill. Children newly diagnosed with cancer may experience embarrassment, anger, withdrawal, depression and self-blame. Art therapy at this stage offers a supportive approach to help patients express troubling feelings and to "regain some sense of bodily integrity and self-worth" (p. 80). Councill describes the use of art therapy with a five year old girl as an intervention in preparing her for surgery. Both the artwork and the child's behaviour in the art therapy sessions, Councill notes, reflected the child's attempt to come to terms with what was happening to her as a result of the illness. Dealing with issues indirectly in art and metaphoric play allows for the emergence of feelings without overwhelming a child's "fragile defences" (p. 81). The artwork of a preadolescent boy involved in art therapy following the removal of a brain tumour is described by Councill as reflecting the boy's sense of withdrawal and of feeling overwhelmed by the disfiguring and disabling aspects of his treatment. The boy's artwork, consisting of a series of clay heads described by him as "space aliens" (p. 81), are interpreted by the author as representing the boy's perception of himself as an alien creature as a result of his

operation. Art therapy provided the boy with an alternative avenue of communication, allowing the expression of his feelings in the safe displacement of art-making. Art therapy also enabled medical staff to better understand the boy's withdrawn and non-compliant behaviour.

The middle phase of cancer treatment presents stresses relating to the prolonged nature of treatment (Councill, 1993). For children at this stage, prolonged discomfort, frequent hospitalisations or confinement at home can lead to social isolation, feelings of helplessness and despair (Chesler, 1987). Art therapy intervention in the middle phase is aimed at supporting the child throughout the long-term stress of treatment by helping to restore the patient's sense of self and providing an outlet for the reflection of feelings about loss. Councill describes the use of art as a form of symbolic defence by a child experiencing difficulties in complying with treatment and who suffered the "trauma and humiliation" of having to be forced (p. 82). Another patient is described as using art to distance himself from his illness, illustrating the "adaptive use of denial in coping with cancer diagnosis and treatment" (p. 83). For an adolescent patient, involvement in art was helpful in increasing self-confidence and in providing an opportunity to work through some of the developmental issues appropriate to this stage, such as concerns with identity, sexuality and capacity for relatedness.

Relapse and palliative care, according to Councill, are periods of heightened uncertainty during which anger and an increased sense of isolation can resurface. Art therapy can be helpful in facilitating communication which "often breaks down at this time" (p. 85). Art

therapy provides the terminally ill patient with an opportunity to give expression to profound feelings associated with an awareness of and ambivalence about impending death. Expression in art and the relationship with the art therapist are seen as providing the patient with a strong support when "words are too difficult to say or hear" (p. 85). Art therapy with a terminally ill boy is described as providing a vehicle for the expression of feelings of loneliness and anger engendered by a separation from the family. Through the expression and acceptance of his feelings, the boy was able to overcome some of his underlying anxiety, gaining a sense of trust through the therapist's support in the art therapy sessions. For another terminally ill patient resistant to talking openly about her feelings, art therapy provided an opportunity to sublimate concerns about impending death in the art. In the case of uncommunicative patients, Councilll notes, the image reflects what the artist is unwilling or unable to put into words.

Conclusion

Art therapy in the medical setting is provided in recognition of the need for psychosocial intervention, in addition to medical intervention, for patients who are physically ill (DiCowden, 1987). Traditionally, art therapists have used art to identify psychopathology and to help patients resolve inner conflict. The medical patient may not only need to resolve internal conflict, but also to negotiate physical illness and disability in order to continue to grow and develop as a person (Councilll, 1993). The practise of art therapy with physically ill patients has developed in recognition of the emotional effects of illness, the limitations of the

medical model in addressing the non-medical needs of patients and the importance of addressing psychosocial needs. Art therapy provides the patient with an opportunity to express, communicate and work through his or her feelings about being ill (Skaife, 1988), as well as to actively participate in working towards a physical, emotional and spiritual amelioration (Bussard et al. 1989). Through involvement in art, the patient's concerns are revealed and may be shared with others, thus offering staff and family a new perspective from which to see and understand the patient and his or her experiences.

Art therapy with physically ill children provides the child with a means for relating concerns about the illness, the experience of hospitalisation and separation from home (Landgarten, 1981). Art plays an important part in the social, emotional, physical and cognitive development of children. It is a well-accepted way of helping children to cope with the stresses of hospitalisation and physical disability (Oppenheim Cameron et al., 1984), helping children express feelings about illness, as a means of diversion and relaxation and to strengthen self-esteem (Radziewicz & Schneider, 1992). Art therapy in the medical setting is useful as a means of assessment, prevention and therapeutic intervention (Oppenheim Cameron et al., 1984), offering physically ill children an alternative psychosocial approach which goes beyond the verbal level and allows for the exploration and expression of concerns associated with the child's experience of illness. In the process of making and discussing art work, children are able to deal with potentially difficult issues at a safe distance (Oppenheim Cameron et al., 1984). Throughout this process, the art therapist supports the child in his or her exploration and working

through of issues associated with illness. Art therapy with terminally ill children allows for the expression of powerful emotions experienced in relation to serious illness and dying and which are difficult to articulate verbally (Bertoia & Allan, 1988; Corr & Corr, 1985; Council, 1993). Involvement in art allows for the development of a supportive relationship between the therapist and the terminally ill child (Mitchell Hodges, 1981) and facilitates the expression of concerns such as fear of pain, death or the unknown. Involvement in art provides opportunities for channelling, as opposed to expending, energy in unproductive ways (Schmitt & Guzzino). It can help to alleviate a sense of loneliness and isolation and it can provide others with a greater understanding of the terminally ill child's inner-world issues (Bertoia & Allan, 1988).

Art therapy in the paediatric oncology setting has an important role to play in addressing the psychosocial needs of children with cancer. Participation in artwork supports ongoing social and emotional development, providing opportunities for self-expression and communication. In art therapy, patients are given opportunities for choice and control and for achieving a sense of mastery over feelings about illness and treatment. Art therapy is a valuable way of maintaining communication with the treatment team and of increasing the awareness of others of the child's subjective experiences of illness (Council, 1993; Cotton, 1985; Sourkes, 1991; Walker, 1989). The practice of art therapy in the paediatric oncology setting differs from art therapy in more traditional settings in several ways. The primacy of medical procedures, the child's physical limitations and the emotional stress of the patient and family all have an impact on the therapeutic process (Cotton, 1985; Council, 1993).

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The traditional boundaries of art therapy may not be available and medical procedures and their effects on the child can disrupt participation in art therapy. The role of the art therapist in paediatric oncology, according to Councill, is as a support person who is familiar with the emotional consequences of diagnosis and treatment, sensitive to the patient's graphic messages and who trusts in the value of open-ended creativity. The art therapist's evaluative skills can help the medical team identify psychological and behavioural problems that can affect a child's response to diagnosis and medical intervention (Councill, 1993). As part of the treatment team, the art therapist can provide a "uniquely humanising" influence in the midst of an experience that threatens the child's sense of self and trust in the world (Rollins, 1990).

Chapter 3: Research Design

Methodology

The research was designed as a descriptive, exploratory study to assess the potential role of art therapy in paediatric oncology. A qualitative methodology framework was used to investigate the research questions. Exploratory studies are frequently conducted when there is not sufficient information about the research topic and are used to develop an accurate picture of the research subject, providing background information about the issues in question (Sarantakos, 1993). A core feature of qualitative research is that satisfactory explanations require a substantial appreciation of the perspectives of the informants. An exploratory approach is used to discover informants' perceptions as the basis for analysing the phenomena under investigation (Allan, 1991).

Since the purpose of this study was to address an area which is relatively new and understudied, namely, art therapy in the medical setting, an exploratory approach was warranted. Such an approach allowed for a detailed description of the perceptions of staff in a wide range of areas which included: the paediatric oncology environment, the experience of cancer for the child and family, the psychosocial needs of the child and the role of art and art therapy in meeting the psychosocial needs of paediatric cancer patients. Basic questions such as: Is there a role for art therapy in this setting?, Where is art therapy needed?, How could art therapy be incorporated? helped formulate the methodological design of the research. In order to assess the viability of art therapy in addressing

the psychosocial needs of paediatric cancer patients, the following areas would need to be explored : What is the experience of cancer for the child? What issues face a child diagnosed with cancer? What are the psychosocial needs of paediatric cancer patients? How are these needs currently met? Where are they not being met? How do staff perceive art therapy with regard to meeting the psychosocial needs of paediatric cancer patients?

A proposal was written to research staff perceptions of the usefulness of art therapy to address the psychosocial needs of paediatric cancer patients. Approval was granted for the conduct of the research from the relevant ethics committees, with recommendations by the hospital ethics committee that interviews not be taped and that I contact the director of nursing to obtain approval for the participation of nursing staff in the research. The director was concerned that the involvement of nursing staff in the study would interfere with their work. Approval for participation was given on the condition that I involve no more than two clinical nurses (whose prime role is patient contact) and that interviews take place on a weekend, when the workload is less demanding (some children go home over the weekend). All other informants, with the exception of the physician, were required to obtain written approval for participation in the research from their own heads of department (Appendix I).

The original proposal was written with the aim of researching the usefulness of art therapy in paediatric oncology from the perspectives of staff working in the oncology unit. I planned to interview a selection of

staff who worked in the unit and provide staff with an opportunity to evaluate the use of art therapy following an art therapy presentation component. On completion of all interviews there was little available data on art therapy as compared to the amount of data on patient and staff issues and psychosocial services. The collection of such rich data reflecting the experience of cancer not only for patients, but also for the family and staff, suggested the need for a modification of the research process. The focus of the research shifted from an assessment of the usefulness of art therapy from the perspectives of staff, to an assessment of the feasibility of art therapy, made on the basis of informants' perceptions of the use of art and art therapy as well as on identified psychosocial needs of paediatric cancer patients and gaps in psychosocial services. As a result, the research has two major areas of focus - (i) an evaluation of psychosocial services and (ii) an assessment of the feasibility of art therapy as a psychosocial service in paediatric oncology.

Sample

In deciding what kind of sample to use in the research, it seemed appropriate to include staff from all areas working in the unit. Preliminary discussions with the head of the oncology department and the clinical nurse specialist (whose role is mainly managerial and to whom I was referred for help in setting up the research), informed me of the existence of a team consisting of medical, nursing and allied health staff. I felt it would be important to have the perspectives of staff from these three areas. A representative sample of thirteen informants was planned, consisting of one consultant physician, four nurses (clinical nurse specialist, liaison nurse and two clinical nurses), a social worker,

an occupational therapist, a school teacher, a chaplain, two children's activities coordinators, a physiotherapist and a dietician. The selection of the particular doctor was recommended by unit management, and the nursing informants were suggested by the clinical nurse specialist who felt they would be suitable because of the length of time worked in the unit (a minimum of five years) and their specialist knowledge of the area. The clinical nurse specialist volunteered to participate in the research. All allied health team members were identified as potential informants jointly by the clinical nurse specialist and myself. Each potential informant was approached individually to discuss the proposed research and to obtain their consent should they decide to participate. With the exception of one person, all staff members approached agreed to participate, on condition that their own heads of department granted approval (which was subsequently the case). One staff member was unable to participate due to approaching long-service leave, however a replacement was found from the same profession.

Data Collection

In order to investigate the research questions, a survey approach was chosen, using interviews and memos as the tools for the collection and recording of data. The original proposal for the research contained a three-stage method of data collection, involving (i) interviews, (ii) an art therapy presentation, and (iii) questionnaires. On completion of stage one (interviews with informants), the research process was modified and stages two and three were eliminated.

Prior to the commencement of interviews, arrangements were made with

individual informants in regard to the conduct of interviews. Informants were notified that the interview would take approximately one and a half hours and if an informant needed to leave during the interview session, the interview would be rescheduled for another time. Given the exploratory nature of the research, a semi-structured interview design was chosen which would cover the same basic areas for all informants (providing consistency of data) while allowing for variability in responses and the expression of individual perspectives. Semi-structured interviewing is considered a useful method of data collection in qualitative research because of its openness and interviewee-guided mode (Sarantakos, 1993), providing the researcher with a flexible framework within which participants can express "their own understandings in their own terms" (Bernheimer, 1986, p. 226-7). Although certain types of information were sought from all informants, the particular phrasing and order of questions in each interview was determined by the informant's willingness and readiness to discuss a certain topic (Bernheimer, 1986). The flexibility of this approach also allowed for the collection of a broad range of information, resulting in richer data. In addition to interviews, I used memos as a system of recording ideas which were formulated during the data collection process. Recording of ideas and cross-referencing of data led to some modifications of the ongoing data collection process.

Interviews were designed to collect data in three areas: professional background, patient information and art and art therapy. Appendix IV lists the basic questions covered in interviews. Information sought on professional background included a description of the informant's role, the length of time working in oncology, the level of patient contact and

evaluation of the role (eg. what are the limitations of the role, what is difficult or stressful, what is enjoyable about the role). Information on patients included the impact of cancer on the child and the family, issues facing the child, the psychosocial needs of the child and ways to address these needs. Art and art therapy questions included the role of art in paediatric oncology and informants' perceptions of art therapy (including understanding and experience of art therapy and whether it is appropriate with paediatric cancer patients). For all three areas, interview questions were designed with the aim of obtaining both descriptive and evaluative data i.e. factual information as well as the personal perceptions, observations and attitudes of informants. In addition to providing richer data for analysis, this approach allowed me to understand more fully the particular environment and the people who work in it, to gain insight into what it is like to work in the area, and to appreciate some of the issues which face staff, patients and families alike. All of these aspects, I felt, should be an integral part of the research, in order to make a reasonable assessment of the feasibility of art therapy in this setting.

Interviews were conducted at a rate of approximately two per week. Data was recorded in the form of hand-written notes, following the recommendation of the ethics committee not to tape-record interviews. This was at times a rather cumbersome process but did not seem to adversely affect the amount of data I was able to record. My impression of interview situations was that in the absence of a tape-recorder, and with the focus on note-taking, informants were relaxed and open in their responses and almost invariably provided a wealth of information in response to the questions.

Data Analysis

The data analysis process used in the research was concerned with both the compilation of factual data and the identification of themes and trends as emerging from informants' perceptions. Significant comments were noted as indications of an emergent trend or which identified deviations to these trends. Data reflecting informants' perceptions on the paediatric oncology environment and the significance of the data to the area of enquiry (the potential role of art therapy in this environment) was the main focus of the data analysis process. Collection and analysis of data occurred simultaneously. As interviews proceeded, modifications within each of the three topic areas of the interview schedule were made, by introducing new questions into interviews, or eliminating questions I felt to be insignificant. Modifications were made if an informant introduced a new and previously unrecorded aspect which was relevant to the research and which seemed worthy of further investigation in subsequent interviews. The process of data analysis involved ordering of sections, labelling of responses, and the identification of categories, allowing thematic connections to be made both within and among interviews. Coding was used to categorise or classify the text. Pattern codes (Miles & Huberman, 1984) are used to identify an emergent theme and to help reduce and analyse data, directing the researcher towards trends, themes, patterns and causal processes (in Sarantakos, 1993, p.304). Memos were used to define the concept which the code represented, indicating its significance to the research. A filing system was employed using location indicators for the retrieval of data.

Steps in data analysis

Each interview was typed verbatim in three separate sections, reflecting the three sections of the interview schedule (professional background, patient background and art and art therapy and given a letter code (A to M). Each section of the interview was given a number code (1 for professional background, 2 for patient background and 3 for art and art therapy) and for each section, line numbers were added to the text. Categories were identified and listed separately with an identifying letter, interview section number and line number code. Cross-referencing of categories allowed for the identification of broad categories (patient, family, staff and psychosocial services) which were used to contain sub-categories of data identified in the three areas of each interview. Repetitions in the data were amalgamated into existing categories and new categories were created with the identification of additional data. The broad patient category, for example, was used to file data from all interviews which related to the child, such as the age and personality of the child, the impact of the illness, issues which emerge for children with cancer, stages of the illness and the psychosocial needs of the child. Data was further categorised into descriptive (factual information) and evaluative (informants' perceptions) data. On completion of this process, (data categorised and areas of interest to the research identified) a detailed description of the data and its emergent themes was made.

Reliability and Validity

In order to address issues of reliability and validity in qualitative research,

Guba and Lincoln (1982) suggest four factors need to be considered: credibility, transferability, dependability and conformability. Credibility is achieved when informants find the researcher's analysis and interpretation represent the informants' realities appropriately. Transferability of data applies when findings of the research can be applied to a context outside the study situation. Dependability refers to the extent that the study can be repeated and similar findings reached. Although the nature of qualitative research design prevents exact replication of a study, the researcher conveys dependability by clearly detailing the research procedures and findings through accurate and faithful recording throughout all phases of the study. Guba and Lincoln (1982) define confirmability in terms of whether the data objectively represents the informant's reality. To achieve this, they suggest the use of triangulation and the practice of reflexivity, by which the researcher clarifies his or her underlying assumptions about the research subject, the reasons for formulating the study in a particular way as well as his or her assumptions and biases about the context or problem.

Relying solely on the perceptions of informants who work in the setting in which the research is based may have had an impact on the reliability and validity of the data. Since I based the collection and analysis of data on a single interview with each informant, I have had to assume that informants reflected their perceptions accurately at the time of interview. Authenticity of perceptions in this kind of research is, however, as valued as theoretical accuracy. Informants' perceptions could be expected to vary according to the individual's experience, personality, attitude to work, level of stress, relationship with other staff, patients and families. Perceptions of people are not fixed and measurable and staff working in

the area of paediatric oncology are faced constantly with a range of issues in respect of which their perceptions could be expected to vary. The demands of the job, the approach of staff to their work, the needs of patients and families are not static and predictable and data reflects what informants had to say in a particular moment. Validity and reliability comes in part from collecting data from a cross section of staff (medical, nursing and psychosocial) and from analysing the data to identify themes, trends and anomalies. In writing up the findings of the research, the data was used both to describe the individual's point of view and to provide an overall impression of the situation, which, if not completely accurate for all staff, patients and families, could be considered as leading to a broader understanding of the issues involved in the overall experience of childhood cancer.

Ethical Considerations

The idea of the research was discussed initially with each informant. Informants in the study were given written documentation with details of the nature and purpose of the study (Appendix II). When a decision was made to modify the research process, informants were notified in writing of the changes to be made, namely, that the amount of time required for participation would be shortened. Informants who agreed to participate in the research signed a written consent form (Appendix III). Participation was purely voluntary and informants had the right to withdraw from the study at any time. Informants were assured that the researcher would employ every possible effort to ensure confidentiality. Codes were used instead of names on the transcribed data and in the final

report, every effort was made to avoid identification of individuals where identification would be considered inappropriate. A copy of the final research report will be made available to all informants.

Limitations of the Research

Given the nature and focus of the study, generalizability of the findings to settings beyond the context of the research study is not applicable. Further research would identify the extent to which the findings of the present study are applicable and generalisable, for example, to other areas of the hospital and to other similar patient populations.

As any research process is necessarily limited in scope, this particular research was limited in the extent to which the feasibility of art therapy could be explored. Exploratory research in the area of art therapy in paediatric oncology could involve a series of research steps, such as:

- a. interviewing staff
- b. interviewing the patient and the family in order to understand the subjective experience of illness.
- c. conducting a needs assessment to identify psychosocial needs from the perspectives of staff, the patient and the family
- d. implementing a pilot programme in art therapy to address identified needs
- e. evaluation of the programme and identification of areas for further investigation.

The present research was concerned only with step (a), interviewing staff in order to obtain information about the setting, the patient population, the illness, the impact of illness, issues for the child and family, psychosocial needs and how these are addressed, and the role of art and art therapy in addressing psychosocial needs of paediatric cancer patients. The findings of the research are limited in as much as only staff perceptions have provided the data. Richer data would have been obtained if the research included interviewing patients and families to explore such areas as the experience of illness, the meaning of the illness, identification of psychosocial needs and the effectiveness of psychosocial services according to the perceptions of the patient and the family.

Using only one interview for each informant restricted the amount of data collected. It may have been more appropriate to spread the interview schedule over two interviews, asking for data on professional background and patient information in the first interview and data on psychosocial services, art and art therapy in the second. Alternatively, the first interview could have explored the overall environment and identified themes, with the second interview used to explore themes in greater detail.

In the area of informants' perceptions of art and art therapy, I realised after the interviewing, that I had made an assumption about the level of awareness and understanding of art therapy by staff. The original plan was to introduce informants to the practise of art therapy by providing an opportunity for their participation in an art therapy information session, demonstrating the use of art therapy with physically or chronically ill

children. This plan was abandoned, however, because of time constraints and the problem of researcher bias affecting the data. Another approach could have been the proposal of a programme using art to explore and identify the psychosocial needs of patients from the perspectives of both staff and patients. In this research, therefore, the assumption I had made limited the extent to which informants' perceptions on the role of art therapy could be considered as useful data for assessing the feasibility of art therapy in paediatric oncology.

Throughout the entire research process, divergent areas of interest were uncovered and themes were identified which I felt to be worthy of further investigation, but which could not be dealt with in the present study. The most obvious area which has not been included in this research is the issue of addressing the psychosocial needs of the family. Although there was a fair amount of data on the impact of childhood cancer on parents and parental coping, as well as indications that the psychosocial needs of the family are not easily met, a decision was made to focus on the patient, in terms of identifying patient needs, assessing how needs are met and whether they could be met more effectively. The purpose of the research was not to look closely at individual issues and areas of need, but rather to focus on broader issues as a basis for assessing the feasibility of art therapy in a setting where it has not been practised before. Despite these limitations, however, a valuable outcome of this research is that it helps to identify areas for further investigation.

Timetable of Research Activities

December 1993: Edith Cowan University Ethics Committee approval

March 1994: Hospital Ethics Committee and approval

April 1994 : Approval from hospital department heads

April - June 1994: Data Collection

November 1995: Completion of research report

Chapter 4: Results

1. The paediatric oncology unit

The oncology unit was established in 1983 and treats cancer-related illnesses (eg. blood disorders such as leukaemia and solid tumours such as bone, brain and kidney tumours) as well as non-malignant blood disorders (eg. haemophilia) in children aged 0 to 17 years. The unit has a total of 21 beds for patients, including 4 day-care beds for children undergoing same-day treatment. There are two separate rooms for terminally ill children and the family, if palliative care is continued in the hospital. The number of patients involved in treatment, including those in a follow-up treatment programme, total approximately 500. An average of 50 new patients are diagnosed with cancer each year. All age groups were said to be fairly evenly represented (infants, toddlers, preschool, school-age and adolescents), although in any one year the distribution may vary (eg. in 1994 the unit treated mostly school-age children). Survival rates for cancer were given as between 50–80%, depending on the illness. The number of deaths from cancer averages out at 14–16 per year. In 1993 there were 19 deaths. In 1994, 3 deaths had occurred between January and November. The treatment period for cancer varies according to the type of cancer. The treatment period for leukaemia was given as (on average) between 2 and 3 years and for a solid tumour between six months and two years. The amount of contact which each child has with the hospital, as either an inpatient or outpatient, also varies. A child diagnosed with leukaemia, for example, spends up to 10 days in hospital for the initial treatment, followed by regular treatment as

an outpatient: "The first seven months are busy, after that [treatment involves] once a month maintenance"(M). Some children may require more frequent hospitalisation, as for example, a child in treatment for a tumour needing to be hospitalised five days in every three weeks. The longest period of hospitalisation is generally for children who have undergone a bone marrow transplant. Following a transplant, patients are isolated in a sterile environment (laminar flow) for four to six weeks to protect them from infection.

The oncology team consists of medical, nursing and allied health staff. Doctors in the team are consultants(3), registrars and residents. The nursing team consists of a clinical nurse specialist, a liaison sister and clinical nurses. The allied health team consists of two physiotherapists, a dietician, an occupational therapist, a social worker, two children's activities coordinators, a teacher and two chaplains. Some of the allied health staff work in other areas of the hospital, in addition to oncology (occupational therapist, social worker, physiotherapists, chaplains).The unit offers both medical and psychosocial care for children and the family, from initial diagnosis through to "whatever outcome": follow-up for cure, relapse, progress of the disease to death and bereavement for parents(M).

2. The experience of illness: impact and coping

The impact of cancer on the child

Childhood cancer is a serious chronic illness, requiring a treatment period

of between six months and three years. The abrupt change of circumstances which follows a diagnosis of cancer has a wide-reaching impact on the child affecting the child's physical, psychological, social and emotional functioning. With the onset of illness, children were said to "go from being well to extremely ill in a short time"(I). Children who are ill are often "no longer able to do the things they used to"(I). Younger children especially may "forget what it was like to live a normal life"(I). The experience of being ill over the long treatment period was said to have the effect of "maturing the children"(M)(B). In addition, the experience of suffering has a "refining effect" which changes the child over the course of the treatment period(K). The age of the child at diagnosis as well as their cognitive level was said to influence the impact which the illness has on the child as well as the meaning of the illness for the child(F). Informants comments on each age group, (infants, toddlers, preschool, school-age and adolescence) are tabled in Appendix V. On the basis of these comments, it would appear that the younger the child, the less psychological impact the illness has on the child. Older school-age children and adolescents were said to be most affected by the illness. Infants (up to 18 months) are "generally immune"(F) from the psychosocial impact of cancer and normally "sail through treatment"(M). In the Toddler age group (18 months to 3 years), children may experience behavioural reactions such as enuresis(H). Children between the ages of 2 and 4 years were said to be "the most difficult age-group for parents" with behavioural problems(A). Preschool children (3 to 5 years) are aware of the severity of the illness "to some degree" which they realise "via the way they are treated"(H). This group was said to show reactions such as anger towards the mother(M) and regression (some give up walking) (C).

Overall however, preschool children were said to "get on with things"(F) and it is thought that there are no long-term consequences for the future(H). Staff comments on school-age children (6-12 years) suggest that younger school-age children cope fairly well. Up to age six or seven years, for example, "they are reasonably okay if allowed to talk"(J). Older children (over the age of 10) have a "greater awareness of ill-life versus normal life"(I) and are "more preoccupied with the illness and its implications"(I). The "biggest problem group"(M) was said to be children over the age of eleven years. Adolescents were described by one informant as "the worst age group" because the illness affects the patient at an age when potentially difficult issues associated with adolescence were emerging: "We can see all their problems with adolescence plus the impact of diagnosis and issues of body-image"(M).

The differences in how children are affected by the diagnosis and treatment of cancer and in the meaning which the illness has for the individual child appear to be closely related to the age of the child. Older children have a greater capacity for understanding the illness and its implications and the impact of cancer therefore, is greater for this age group than for younger children. In addition to the age and cognitive level of children, two other factors were identified by informants as influencing the impact which cancer has on children. According to one informant, the impact is related more to the illness itself than to the age of the child(H). Other comments suggest that the impact of cancer is influenced more by the individual child and the coping styles of the child and family.

Within the overall experience of the illness, informants identified three specific areas which were said to have a major impact on the child: hospitalisation, treatments and procedures and physical changes. Table 1 outlines the impact of the diagnosis and treatment of cancer on the child.

(i) Hospitalisation

The major impact of hospitalisation or frequent visits to the hospital as an outpatient can be described as a series of losses with which the child is faced and which appear to have an effect on the child at social, emotional and psychological levels. An enforced hospital stay involves a loss of boundaries(D) and can be seen by the child as a "term of detention", or as a period of "biding time"(J). Hospitalisation over a long period of time was said to have the potential of "warping" the development of the child and of encouraging negative behaviours(E). Socially and emotionally, children, whether as inpatients or outpatients, are affected by losses such as being away from home and school, limitations on social interaction or by a general disruption to their daily routine(D). For the older child, the long-term nature of the illness can affect normal social activities to the extent that contact with friends and the social network is lost(M).

(ii) Treatments and procedures

The treatment required for cancer and the procedures which children undergo as part of treatment can be difficult and painful for children and have both physical and psychological consequences. Physical reactions to treatments and procedures were reported as the pain of procedures such

Crisis points:

Diagnosis, relapse, remission, terminal illness

Hospitalisation:

Separation, isolation

Loss of boundaries, loss of control, loss of routine

Treatment:

Long-term

Pain, discomfort, nausea and vomiting

Loss of appetite

Changes in appearance

Life-style:

Disruptions to home, school, family life

Over-protectiveness, over-indulgence by parents

Loss of peer support

Decreased social interaction

Self - perception:

Shyness, embarrassment

Lowered self-esteem

Uncertainty about the future

Behavioural and emotional problems:

Tantrums, non-compliance, school refusal

Loss of control over eating

anger, aggression toward others

lack of communication

withdrawal

fear, anxiety, stress,

depression and despair

Table 1. Impact of Cancer on the Child

as blood tests, lumbar punctures and bone marrow aspirations ("the worst from the child's point of view"(H) and nausea as a result of chemotherapy treatment. Psychological reactions such as fear, anxiety and

stress are possible in relation to medical procedures and towards staff who carry out these procedures(M). Children can be anxious about a procedure because "they don't know what's going to happen"(I) or stressed in anticipation of a procedure to be carried out the following day(H). Nausea experienced as a side-effect of chemotherapy was also said to have psychological repercussions. Some children develop nausea in anticipation of chemotherapy treatment, increasing the level of stress associated with treatment. Children's reactions to treatment were reported as "knowing they need it and accepting it"(J). Others however, were said to "fight it" despite knowing that treatment is necessary(I). The treatment of cancer was identified as an area in which "children don't have much control" because "if they want to get better they have to succumb"(I).

(iii) Physical changes

Physical changes which occur as a result of treatment were said to have a big impact on the child: "What is happening physically has repercussions emotionally"(C). Body image issues are significant for the child in terms of their awareness of the perceptions of others towards the child. Hair loss, a side-effect of chemotherapy treatment, was most frequently mentioned as having a major impact on the child: "I find it has the biggest impact of all"(M). Children's reactions to hair loss such as "feeling shy and embarrassed" were said to be normal, and this issue is routinely addressed through counselling(M) and in play sessions(D). Other physical changes reported as having an impact on the child are changing body shape and the effects of surgery(C).

How children cope with illness and treatment

Informants' comments on how children cope with the illness and treatment identified two differing points of view in regard to the extent of coping and the severity of problems experienced by children and adolescents. The responses to this area of investigation were categorised as: (i) children cope well with the illness and (ii) children experience difficulties in coping. Informants' perceptions of children's coping are tabled in Appendix VI. Children were said to cope well with the illness and treatment by some informants: "Children cope very well, given how foreign it is"(H). Children were said to adapt "because they have to"(H). It is rare for children to become fearful and withdrawn(H) and children who do, respond well to psychosocial interventions(F). Factors identified as influencing how children cope include the level of family support: "Some children have a lot of support"(I); and the ability of children to communicate openly: "Children cope well when they can talk about their treatment"(J). Having a supportive family, however, does not guarantee the child will cope well with the experience of illness (I). Interventions for children who experience difficulties coping were said to increase children's ability to cope: "Stress [related to procedures] gets less as we get to know which children require treatment in the broad sense"(H).

Several informants expressed the view that children diagnosed with cancer experience difficulties in coping with illness and treatment. The older the child, moreover, the more likely it is that the child will experience problems: "a lot of adolescents don't cope"(J). The areas in which children were said to experience difficulty coping were listed as:

treatments and procedures; changes in physical appearance; and with the overall experience of illness and hospitalisation. The most frequently reported areas of difficulty were in relation to treatments and procedures and physical changes as a result of treatment. Stress is a common reaction of children to the painful and distressing aspects of treatment (H). Some children were reported as becoming "resistant and difficult"(I) or "non-compliant"(J) in relation to treatment. Physical changes which occur as a result of treatment and which typically cause children to feel self-conscious can affect some children more seriously as, for example, when the child is reluctant to be seen in public or to return to school(I). Depression was reported as a common reaction to the overall experience of illness and hospitalisation. A lot of children were said to experience depression(I) and despair(K) as well as a lack of motivation to participate in normal childhood activities(K): "[These children] don't feel like doing anything"(I). Children who are "waiting for treatment to finish"(M) can become frustrated and angry and could be aggressive towards parents and staff(J). Other children may react by becoming withdrawn and uncommunicative and "difficult for others to cope with"(M).

The impact of cancer on the family

The impact of cancer on the family is influenced by the family's personal understanding and experience of the illness. Fear and a high rate of death were said to be commonly associated with cancer. The family's immediate reaction, that the child is going to die, was said to be passed on via the media in particular and society in general(J)(M)(I). A diagnosis of cancer was said to affect the whole family. It was noted that it has a "huge

impact" on family life, "completely changing the dynamics of the family"(I). Such "disruption to normality" affects home, work and social life: "Nothing remains the same or will ever go back [to how it was]"(G). The impact of the illness was said to have a "strong negative effect" on siblings, especially when the child dies(A). Siblings can be adversely affected by parents giving extra attention to the ill child: "It's difficult for parents to cope with giving time to both the ill child as well as to the family"(M). Parents' recognition of emotional needs was said to be "not a high priority" since they are primarily involved with meeting the medical needs of the child(D).

Parental reactions to diagnosis were said to include shock, fear and confusion. Parents are faced with having to cope when they are overwhelmed with information and fearful that the child may die(M). Some parents react by directing their anger toward staff "who are there when they are told their child has cancer"(M). Anger was said to be a reaction in some parents who are unable to accept the diagnosis and need a long time "to come to terms with the illness"(M). Other parents were said to experience feelings of guilt and blame in relation to the onset of the child's illness(J). In addition to the impact of diagnosis, other stages of the illness – remission, relapse and the terminal stage – were said to have "significant impact" on the family(C). Remission was identified as a difficult time for parents since there is "always a possibility the cancer will come back"(A). Relapse was identified as "far worse than initial diagnosis" for parents(C). The impact of terminal illness on the child and family is discussed separately in the following section.

How the family copes with illness and treatment

No two parents react to a diagnosis of cancer in their child in "identically the same way"(B). Some families were said to adapt to the stress of having a child with cancer and as treatment proceeds "settle down with routine"(G). Families who do not cope well were identified as "struggling to adjust to what is happening in their lives"(C). In some cases, fathers of children with cancer were said to experience greater difficulty than mothers because "they get less support" and they are often "not [on the ward] when psychosocial staff are available"(M). Fathers generally have "less input" in treatment than mothers and in some instances, cope by "keeping their distance"(M).

Terminal illness: special circumstances for the child and family

The impact of a diagnosis of terminal illness on the child appears to be related to children's awareness and understanding of death and dying and to the level of communication between the child, family and staff. Table 2 lists informants' perceptions of some of the issues involved in the area of terminal illness. Children's exposure to the issue of death was said to begin "early on" when they first have contact with the oncology unit(M). Up to adolescence, according to one informant, children do not have a fear of death or any perception of what they are losing, nor do they think about what happens after death(F). Adolescents were said to "know where they are at even when they are dying"(M). Some children were said to react to the knowledge that they are dying with "acceptance and peace", while others experience the period of dying as a "terrifying time"(G).

Several informants reported a belief that terminally ill children are aware that they are dying, even if they are not told. Children were said to have

Awareness of diagnosis

Children:
aware that they are dying even if not told

Parents:
difficult to accept ; sometimes deny diagnosis
more difficult for the family than for the child

Staff:
major issue - when children need to be told
diagnosis is more difficult for doctor than for parent

Communication about death and dying

Children:
some children unable or unwilling to discuss

Parents:
difficult to discuss
some refuse to allow communication about death with the child

Staff:
Unit supports open communication
easier to work with family that is open
difficult when parents don't want anything said

Involvement with terminally ill children

Children:
need opportunities to discuss death
talking reduces fear and anger/ increases acceptance

Parent:
may avoid child to avoid discussion of difficult issues
(fear and anxiety; wanting to protect the child; unable to accept diagnosis)

Staff:
terminal illness a specialty area
staff involvement is very individual
difficult to know what sort of involvement to have

Table 2. Issues in Childhood Terminal Illness

"an intuition that they are dying"(H) which is evident through observation of the child(J) and, as one informant believed through observation elsewhere, by what is revealed in their drawings(M). The level of communication between the child, family and staff about death and dying was said to have an impact on the terminally ill child in that, if the child does not have opportunities to discuss his or her concerns, death is unknown and gives rise to fear and anger(G). Concern was expressed by some informants about the ability of children to express their concerns(D) and opportunities available to children to help them express their concerns(K).

A diagnosis of terminal illness was said to be more difficult for parents than for the child because "parents don't expect to bury their own child"(C). Parents were said to react to a diagnosis of terminal illness in a variety of ways. Some parents deny the seriousness of the illness because they are "unable to accept there is no hope", or they avoid telling the child (eg. wanting to protect the child or out of fear) that the child is seriously ill(M). The reactions of parents can also have an impact on the level of involvement which parents have with the terminally ill child. Reactions such as fear and anxiety can be transferred to the child(D) and have the effect of distancing the child to the point where parents feel excluded by the child and unable to offer any support(M). The involvement of both parents with the dying child may be restricted as, for example, a "possessive mother" wanting to be with the child to the exclusion of the father(B). The impact which the death of a child has on the parents and family is influenced among other things, by the ability of parents to "work through in a way that becomes a positive growth

situation instead of breaking up the family"(C). This was recognised as being a difficult task for parents and most parents whose child has died were said to need more support(G). Some parents are able to see something positive come from the death of a child(G), while others were said to feel "left in the lurch" following a death(I).

3. Psychosocial services for the patient and family

The unit's approach towards meeting psychosocial needs

Providing psychosocial support for children with cancer and their families is a major part of the unit's approach towards treating the disease. The broad aim of treatment, according to one informant, is to deliver it in "the best possible setting with the minimum side-effects"(H). Psychosocial care is recognised as important in "helping the child and family to return to normal life as soon as possible" and in ensuring "minimum traumatisation for the child"(H). In addressing the psychosocial needs of the child and family, staff in the oncology unit work as a team, where each person's role is said to "complement, not rival" the roles of other team members(M). Staff are selected to address particular psychosocial issues on the basis of the particular strengths and capabilities of each staff member. The team's approach is based on "knowing who the right person for the job is"(H) and on "picking out the person best suited"(A). The rationale for this way of working was said to be that different people are "good at different things" and "good for different families"(A). Communication among staff about issues that need to be

both formally (at psychosocial meetings) and informally: "If one staff member picks up on a problem it will be referred to other staff"(D). If problems are identified between meetings, particular staff will be asked to intervene: "If problems are spotted, others tell me [and as a result] I become involved"(L). Staff commented on the necessity and effectiveness of both formal and informal communication in addressing the needs of the patient and family. Psychosocial meetings are held once a week with the purpose of discussing and addressing patient, parental, family and treatment problems or concerns. Staff reported that these meetings fulfil several functions: meetings

- i. are "extremely useful" in providing feedback from psychosocial staff to doctors and nurses, as well as from doctors to psychosocial staff via parents(H).
- ii. enable selection of the appropriate staff member to address a particular problem: "If it falls into my brief I'll pick it up"(D).
- iii. provide background information about patients and families to all staff who work with them: "We need to know what's going on at home, medically etc...we are not going to make much progress otherwise"(L).
- iv. allow for better communication of issues: "Communication can get lost if it's only written"(L).
- v. provide an avenue for helping staff deal with stressful issues and for staff to share their feelings about work-related issues: "It's useful to hear other [staff] feel as you do about a particular situation"(L).

The above comments highlight the philosophy of the unit towards meeting the psychosocial needs of the patient and family. Psychosocial needs are addressed within the context of a team approach, with all staff

playing some role in either identifying or addressing these needs as they arise.

Staff roles

In order to understand the role of the team in addressing the psychosocial needs of the patient and family, each informant was asked to define his or her individual role within the team. The responses provided by each informant have been retained in separate categories (occupational therapist, social worker, clinical nurse etc.) rather than amalgamating them into groups (psychosocial, nursing, medical). This system was chosen as a way of highlighting the individual's own perspective on and contribution to the delivery of services in the unit. In addition, presentation of data from each interview allows for the identification of the extent of psychosocial involvement within each role. Psychosocial services, although not a formally defined part of the role, may be offered indirectly by an individual team member. For example, the dietician's role was defined as "[helping the child] maintain a good weight" but which also involves "building a relationship with the child in order to work more effectively with him or her". The extent of psychosocial involvement within the role of each team member was seen to vary, however all staff could be said to have some involvement at this level. In analysing the data relating to the definition of roles, informants' comments were found to be both descriptive and evaluative. Descriptive comments about the role include the main client group worked with (i.e. children, adolescents, siblings, parents, staff) and a description of what is involved in performing the role. Evaluative comments provide a more

patient." Other staff described her role as "helping to normalise everything" and "giving the child choices"(F). Through her involvement with children in play activities, the CAC is able to "find out how children are going, how they are responding emotionally and developmentally"(F). She was said to "help children talk about their feelings" and to help build their self-esteem(I). General information about how the child is coping is referred back to the team(F), and direct referrals are made to the occupational therapist for children seen as experiencing "major adjustment problems." Although the role is traditionally seen as diversional, the CAC spoke of offering activities which have both a diversional and therapeutic focus. The role was said to have moved from a crisis management to a preventive management focus, with more emphasis on working therapeutically with children. The CAC reported wanting to develop greater skill in "drawing out children" in order to be able to offer more effective emotional support for the child. Most informants saw the role of the CAC as being valuable: "The play leader is excellent"(J). Perceptions of her role varied among informants, some seeing the role as closer to diversional, others reporting a greater emphasis on therapeutic interaction. The CAC was referred to variously as the "play leader", the "play lady" and the "play therapist". The last title was explained by one informant as "how we see and use them"(F). The CAC herself suggested the use of the title of "play lady" as "a fond thing" which was related to the children's perception of her as "the person who has the keys to the cupboard" and as "probably one of the most favourite people on the ward".

personal insight into how the informant views the role. Informants' comments about their own role are supplemented by comments from other team members where they occur in the data. The order in which the roles are discussed relates to the level of contact with patients and to the extent of involvement with meeting the patients' psychosocial and therapeutic needs as revealed by the data. Informants' comments are presented occasionally as a direct quotation and are not coded. Quotations from other informants are coded in the usual way.

Occupational Therapist

The occupational therapist works mainly with younger children who "present with difficulties", including patients and siblings. Her role was described as "supporting the child's emotional and physical development" by addressing the needs of the child at "cognitive, physical, social and functional levels". The occupational therapist's psychosocial role was said to involve counselling children with problems as a result of illness and treatment, including terminally ill children and siblings.

Children's Activities Coordinator (CAC)

The CAC works mainly with patients. Her role is to "support children with cancer throughout their hospital stay" In addition to "dealing with the daily needs of children"(J), the CAC has "indirect contact" with parents and siblings of children with cancer. She said she offers "support and encouragement" and "time-out" for parents by involving the children in play-room activities. Siblings are encouraged to play while in hospital, to "express how they feel" and to "see what it's like to be a

Children's Activities Coordinator(Research)

In the role of conducting research into the prevention of stress in patients, the CAC(research) works with children undergoing medical procedures. The CAC uses such interventions as relaxation, guided imagery and story-telling. The CAC spoke of her role as fulfilling the needs of children for someone they can trust, "knowing that I'm not going to hurt them."

School Teacher

The teacher's role is to provide continuity of schooling to children who are in hospital, including in-patients, out-patients and siblings. Activities focus on both academic development and pastoral care and include physical education, music and art and craft activities. The role also involves liaison with the child's own school and discussion with parents of school-related issues, such as the child's academic development throughout the illness. The teacher stressed the importance of offering a wide range of activities in order to provide as many opportunities for the child's participation and involvement as possible which in turn addresses other needs of the child such as opportunities for social interaction and creative expression.

Hospital Chaplain

The chaplain's role involves liaison between parents, children and staff, although she said she works "mainly with parents." She described her role as "a very intangible kind of position." For parents, the chaplain said she was "someone they can talk to, someone who will sit with them and take an interest in them." For children, the chaplain is "a friendly

face without a needle behind my back." Requirements of the role of chaplain include the need for "total flexibility" and an awareness of the perceptions of parents and children towards the role: "I never discuss the child's [medical] condition" and "I never bring up the subject of religion – if they do that's fine, we never preach religion."

Social Worker

The social worker's main role is working with the family of paediatric cancer patients. She said she works mainly with parents and occasionally sees adolescents. She described her role as "helping the parents and family adjust to the medical diagnosis." A major part of the social worker's role is to "assess parental relationships as a support mechanism, making sure support is available"(F). Every family is seen by the social worker at an initial interview. The social worker provides counselling to address difficulties regarding the family's adjustment or for problems which arise in the course of the child's treatment. She has a high profile at "crisis times [i.e.] diagnosis, relapse and terminal illness."

Liaison Nurse

The liaison nurse described her involvement as mainly with parents although she has "more input with mothers" than fathers. As liaison nurse, her role is to ensure continuity between the ward, home and school. In performing the role, the liaison nurse functions as a "link-up person" for parents and others to contact in order to address any issues: "Parents know who to contact, they see you as there." In working with parents she said she "helps make sense of the confusion" for parents, helping them to cope with the demands of both the child and the family. In working with children and adolescents, she described her role as

providing them with education about their condition and advice about how to cope.

Doctor

Although the doctor's main focus is treating the medical condition of patients, the role was said to involve "overviewing the child's entire therapy". The extent of psychosocial involvement in the role of the doctor was described as both a matter of time and personal choice, depending on the individual child and the relationship between the child and the doctor: "With some children I have a bigger [psychosocial] role than others...it depends on the relationship with the individual child and family".

Clinical Nurses

The main involvement of clinical nurses is with patients. In their role as nurses they were said to have specialised knowledge of drugs, disease processes and disease outcomes. One of the nurses interviewed said the role involved "being used as a resource person on the ward" on the basis of the level of experience and understanding in the field of oncology nursing. The two nurses interviewed spoke of their psychosocial role in terms of their relationships with parents and children, which in turn is influenced by the perceptions of the family and child towards nurses. Nurses are not generally involved in psychosocial intervention. Their psychosocial role was described as "noticing if there's a need and passing it on"(F).

Physiotherapist

The physiotherapist's main involvement is with in-patients: "initial diagnosis and those that are very ill". She said she has some involvement with parents: "talking to parents about what the child is and isn't able to do." Her involvement at the psychosocial level was described as minimal: "I try to stick to the physiotherapy role since the psychological needs of the child are met by others." An exception would be when "a patient or parent asks me because they have got to know me." The physiotherapist said she would always refer on to psychosocial staff if she perceived a child's need to be beyond the scope of her role.

Dietician

The dietician works with both patients and parents. The role involves the long-term monitoring of patients, providing guidelines and advice about the child's dietary intake, ensuring the maintenance of a good weight and intervention "if things aren't going well." The psychosocial aspect of the job is linked to the relationship which develops as a result of working with the parents and child: "[The dietician] goes from working with food, to building a relationship to making a connection with someone."

Clinical Nurse Specialist(CNS)

The CNS is involved principally with staff in the oncology unit. Her role was described as a coordinator with specialist skills whose job is to liaise between nursing, medical and psychosocial staff. As part of the role, the CNS is responsible for making sure all protocols are followed through, looking at policies and procedures in relation to upgrading and education, conducting and implementing research related to nursing practices as

well as linkage with the "hands-on" nursing and medical staff.

Psychosocial services

Table 3 lists psychosocial services available to paediatric cancer patients and their families as identified by informants.

Service and examples

Diversional activities:

television, video, video games, books,
art & craft activities, hospital radio station

Ward visits:

parents & relatives, community workers (eg police),
sporting personalities and celebrities

Hospital school:

school-based activities, physical education, music, art & craft

Activities with psychosocial staff:

art and craft, cooking, medical play

Preparation for medical procedures:

relaxation, guided imagery, story-telling

Organised events:

campus for patients; camps for siblings; outings for patients and parents

Support groups:

parent support group; Canteen (for adolescent cancer patients,
siblings and family)

Referrals outside the unit:

Psychiatry, outside agencies and professionals (eg, hypnotherapy)

Table 3. Psychosocial Services Available to the Patient and Family

Diversional activities

Diversional activities for patients in the unit are considered to be very important: "[They] stop the child from focussing on the hospital environment"(E). For nursing staff in particular, if the child is "happy and amused" staff "are able to do something else"(J). Diversional activities were said to be readily available to patients either via parents, the children's activities coordinator or "they can help themselves"(D). Books and games for adolescent patients were said to be supplied on "brief visits" from the Adolescent Unit or, if the patient is well enough he or she can visit the unit(J). Staff comments on this area of psychosocial services suggested a level of dissatisfaction with certain aspects. Children were said to watch a lot of video, which is "not that great [because] they get into a rut"(K). One informant suggested changing the ward routine which would involve having the television turned off at certain times(J). Video games were said to be overused in some cases, with the highest participation by lower- and middle-primary school boys(K). The hospital radio station offers a diversion to patients by encouraging the child's participation. According to one informant, however: "they're doing it for the right reasons but they haven't got a clue(J). On the basis of informants' comments, adolescents appear to have fewer opportunities for participation in diversional activities, as one informant suggested: "[The unit] doesn't offer [them] a great deal"(J).

Ward visits

Ward visits by parents and relatives were included by one informant in the area of psychosocial services available to the patient because of the role the family plays in helping to "keep the child happy and amused"(J).

Hospital school

The role of the hospital school is to meet the child's educational, social and emotional needs by fostering academic development and by providing opportunities for social interaction and enjoyment(K). School services address issues such as continuity of schooling for in-patients and school re-entry by liaising with the child's own school. School services were said to be important in "keeping the child occupied" and in providing a "semblance of normality"(J).

Activities with psychosocial staff

Activities for children with psychosocial staff and volunteers were said to have both a diversional and a therapeutic focus. A weekly activities-based group is jointly conducted by the occupational therapist and the childrens' activities coordinator with the purpose of providing opportunities for the child to talk about his or her feelings, allowing staff to get to know the child and any issues they may have, and identifying parents and children who may be at risk of experiencing problems(A). Play activities are offered by the CAC either in the play-room area or on the ward. The CAC said she uses toys, games and art and craft activities both as a diversion and to encourage children's expression. Specific activities such as medical play, dressing dolls, drawing on dolls for the child to "show what's happening" and body tracing were said to have a more therapeutic focus, allowing for example, the expression of concerns relating to treatment and procedures. Hospital volunteers in the unit's outpatients' area offer art and craft activities for children attending the hospital as outpatients. This is an informal group with a primarily diversional focus(M).

Preparation for procedures

The psychosocial needs of children undergoing procedures for treatment are addressed by using interventions such as story-telling, relaxation and guided imagery. This is a recent addition to the range of services provided and at the time of interview was the subject of research into the prevention of stress in children. It appeared to be well regarded as a psychosocial intervention, as the following comment indicates: "What children need is preparation for procedures... story-telling certainly seems to work"(H).

Organised events

Camps, outings and weekends away for patients and the family were established as a way of addressing certain important psychosocial needs (such as social interaction among cancer patients; time-out for parents; recognising the special needs of siblings) which are not easily addressed within the unit. The camp for siblings, for example, was established as "the best way to meet their needs"(A).

Support groups

A parent support group provides parents with a means to address some of the issues associated with having a child with cancer. According to one informant, the group is largely represented by "parents whose child has already ended treatment"(I). Parents who are "highly stressed and needing treatment" were said to be not as involved in the group(I). A support group for adolescent cancer patients (Canteen) was formed to meet the psychosocial needs of adolescents and their families. Before this group was established, according to one informant, the needs of

adolescents "were not well met"(A). Although the group operates outside the hospital, contact with adolescent patients by the organisation is established early on (within a week of diagnosis) and a representative from the group attends the weekly psychosocial meetings in the unit.

Referrals outside the unit

Referrals to psychiatry and to outside agencies or individual professionals were listed by informants as additional services available to patients and families. Referrals outside the oncology unit are made if staff in the unit are unable to address particular issues which arise (eg. relationship difficulties for parents(C), needle phobia in patients(F)). Referrals to psychiatry were seen by some informants as sometimes problematic. Referring patients and families to psychiatry was said to take time(J). In some cases, according to one informant, referrals have been made and "nothing has happened"(I). The perceptions of parents towards their involvement with psychiatry was said to influence the effectiveness of these referrals. Psychiatry is "threatening for some people" and some families "have not wanted to go"(I). This perception was also reflected in a comment from one informant who saw psychiatry as inappropriate for children and families in oncology: "Psychiatry addresses problems of mental illness [and is] not for healthy psyches"(F). Referrals to outside agencies or individuals may be made for parents seeking an alternative means of overcoming problems which arise in the course of the child's treatment. Hypnotherapy, for example, has been used as a way of overcoming a treatment-related problem(F).

Addressing the psychosocial needs of the patient and family

The needs of the patient

The psychosocial needs of the patient were identified by informants as including the need for normality, control, communication and emotional support. Table 4 outlines the general responses of informants in this area.

Children need:

Normality:

to be able to lead as normal a life as possible

to be treated normally by others

Control:

to feel like they have some control over what is happening

Communication:

to have someone to talk to

to feel like they are being listened to

Emotional support:

to feel comfortable and secure

to feel nurtured and protected

to be accepted by peers

Table 4. Psychosocial Needs of Paediatric Patients

Addressing the psychosocial needs of patients

Informants identified several factors considered to be important in order to effectively meet the needs of patients, including knowledge of the child, the development of a supportive relationship and the ability to encourage communication with the child. Children with cancer need to be considered not solely as patients in hospital but within the wider context of life at home, school and their familial and social relationships. In addressing the needs of the patient, background information about the child and family is important, since staff "often have to deal with what went on before the child became ill"(G). In assessing the needs of the child, informants reported, both the child and the particular situation are evaluated individually(J), with consideration given to the child's developmental level and to his or her level of comprehension(J)(M). The environment in which the child undergoes treatment needs to be supportive of the child(K). The unit's approach to providing a supportive environment was said to involve, among other things, "keeping things as normal as possible"(B). Children are encouraged to participate in activities such as schooling while in hospital, or to return to their own school as soon as possible(J). Involvement in activities was said to benefit the child by keeping the child "happy and amused"(J) as well as by addressing the child's need for routine and structure(J) and social interaction(K). In addition to involvement in activities, children were said to need "child-focussed" interventions which address the needs of "the whole child"(K). Children need education about their condition and appropriate counselling(K) such as teaching and advising children how to cope(M). Several informants

identified the child's need for communication and the role of staff in encouraging communication as an important factor in addressing the needs of children. Self-expression and communication of the child's concerns were said to help the child cope with the illness and treatment: "children cope better when they can talk about treatment"(J). Important qualities of staff working in oncology were identified as having both compassion and a positive attitude(K). Maintaining a positive approach in interacting with children was said to be a requirement of working in the unit(K)(J). The development of a relationship between the child and staff is important and necessary in order to work more effectively with the child(L). Informants spoke of the need to "get to know the child before the child will open up and use you as a confidante"(D) or "talk about their feelings"(I).

Addressing the psychosocial needs of the family

The psychosocial needs of the family were said to be addressed either through staff identifying problems and referring the family to the appropriate team member, or by parents approaching psychosocial staff directly. Parents with problems are encouraged to come forward and approach psychosocial staff(J). Addressing the psychosocial needs of the family is considered an important factor in addressing the needs of the child: "in dealing with parents, a lot of problems with the child are dealt with"(D). The following aspects were identified as important for staff who work with the family: knowledge of the family's background(G); understanding of "what the family is going through"(C); acceptance of how the family copes(C); the development of a relationship which allows

staff to "build up trust" with parents(D); and working with the "needs and wants" of the parents(D)

Addressing the psychosocial needs of the terminally ill child and the family

This section is discussed separately because terminal illness is considered to be a "specialty area with other ramifications"(J). The comments which follow reflect informants' perceptions about the needs of the terminally ill child and the family and some of the issues involved in addressing these needs.

Psychosocial care for terminally ill children was said to be "very important, offering quality of life for children who are not going to make it"(H). Staff who work with the terminally ill child and family were said to need experience and knowledge in the area of "death and dying, grief and loss"(C). Staff involvement with the terminally ill patient and the family was described as "more than just a working relationship"(L) where the extent of involvement is "very individual" and is determined more by the child and family than by staff (E). Being able to work closely with terminally ill children was described as "a privilege you have to earn"(E). A major issue for both staff and the family in this area, as identified by informants, relates to children's awareness of their terminal condition and whether or not they are told by staff or parents: "It's a big issue telling a child or not that they are dying"(M). The approach in the unit was said to favour telling the child, with the information being passed on via the doctor rather than "leaving it up to parents"(M). Some children,

however, are not told(M). One informant said the approach towards telling the child was "brutal" but "in most cases it works"(D). Leaving it up to parents to tell the child was said to be "not always positive" because the child can be "very angry" towards the parents as a result(M). Several reasons were given in support of the view that it is better for the child to know, as well as to be able to discuss issues of death and dying openly: "If not talked about, death is unknown and gives rise to fear and anger"(G). For staff working with the family of a terminally ill child, it was said to be "far easier to work with a family that's open"(D). For the child, being able to talk about death was said to help them reach a level of acceptance: "once children can talk about death they relax"(H) which allows them to "let go and say goodbye" more easily(D).

4. Staff perceptions and evaluation of the effectiveness of psychosocial services

Evaluation of psychosocial services

Several informants expressed a belief that oncology is better serviced than other areas within the hospital. Support for the child was said to be higher in oncology and the needs of children with cancer are met "far better than in any other area"(G). Among the reasons given for this perception were that cancer has a higher profile, is better funded and receives more sympathy and support from the public as compared to other illnesses. Some informants suggested this was "unfair"(G), especially since "death is imminent in other areas (eg. chest problems and neo-natal)"(I). Although beyond the scope of this study, an investigation

of the extent to which the psychosocial needs of physically ill children across all areas of the hospital are met would be an interesting area to explore.

Informants' perceptions of psychosocial services available in the unit varied from very effective to ineffective. Psychosocial services, according to some informants, are "on the majority very good"(F) or "excellent"(J). The opportunity to meet the psychosocial needs of patients is "very good"(D) and enables the achievement of the unit's philosophy of supporting the child "most of the time"(F). Problems were said to be addressed by psychosocial staff "if psychosocial staff are made aware of them"(A). Some informants expressed concern regarding the effectiveness of psychosocial services in meeting the needs of the child and family: "The awareness is there but there may be a lack of resources sometimes to follow up"(I). Psychosocial staff, some of whom work part-time in the unit, "always seem really busy and stressed"(I). Part-time staff were said to have other priorities (eg. working in other areas of the hospital) and are "not able to dedicate themselves full-time(D) to addressing the needs of patients and families in oncology. The work of one psychosocial team member was said to be effective mainly because the role is full-time: "she's here on the ward when things are happening"(D). In order to effectively address the needs of the child and family, psychosocial staff need to be available "when the need arises"(D).

Other comments relating to the perceived effectiveness of psychosocial services reflect concerns about the ability of psychosocial staff to meet the needs of the patients and the family. "[Some psychosocial staff] are "not

always able to deal with the needs of children"(B). In some cases, according to one informant, sending children to the occupational therapist or to the play leader is "not enough [because] we sometimes need a psychologist"(F). In meeting the needs of parents, psychosocial staff were said to lack the necessary skills and training: "[psychosocial staff] are not adequately trained for marriage guidance, which is what we need"(F).

Another area of concern which emerged from the data relates to perceptions of the effectiveness of the whole team in working collectively to address psychosocial issues. The psychosocial team was reported as "not helping in [the nurses'] cause"(E) and the medical/nursing team was said to lack sufficient understanding of psychosocial issues(C). One informant observed that nursing staff do not receive enough information or feedback from psychosocial staff about issues that nurses have referred to them. Nurses were said to be "the information gatherers for psychosocial staff who, in return, "tell [the nurses] nothing"(E). Concern was also expressed that issues which are referred by nurses to psychosocial meetings may not be addressed and that psychosocial services were not always available: "[Nurses] can't always use them [so they] tend to use them less"(E). Attendance by medical and nursing staff at psychosocial meetings was identified as an area of concern for some psychosocial staff. Doctors and nurses, one informant commented, should be attending meetings in order to have information "which helps them understand why [for example] families are difficult"(G). Although medical and nursing staff are busy and not always able to attend(D), according to one informant non-attendance by doctors can be interpreted by psychosocial staff as a lack of interest in this area of treatment(E).

Informants' responses to questioning as to whether psychosocial services could be improved, indicated that for some, improving services was either not a possibility or only a limited possibility: "There's not a lot you can do"(J) because "there's a limit to resources"(I) and the needs of patients are "met as best we can possibly give for these times"(G). Some informants reported seeing a need, though not necessarily a possibility, for change. Within this group, the majority of recommended changes was in the area of staffing. Some informants reported a need for a change in psychosocial staff positions from part-time to full-time(F)(G). Other informants recommended employing more psychosocial staff to be available(I). Three informants reported the need for a clinical psychologist to be included on the oncology team. The role of the psychologist was described by one informant as someone who "spends time totally with families and staff and who is able to understand the problems people have here and the pressures that staff are under"(F). Another informant spoke of the need for a psychologist as providing oncology staff with "an expert avenue to refer on straight away, [rather than] being passed on via the system which takes time"(J).

The work environment and challenges to the staff

Oncology was described as a high stress area(C) with a lot of trauma(M). Although a "serious area to work in"(H), informants spoke of working in oncology as a privilege(E), interesting(I), challenging(K) and positive: "It's an area that's always changing [in regard to] treatments and life-expectancy"(J). Informants' comments on working in oncology were categorised in two areas: what is enjoyable about the work and what is

difficult or stressful. The second category includes comments relating to areas of difficulty or stress as either explicitly identified by informants or implied in comments made throughout the course of the interviews.

What is enjoyable for staff

Informants' comments about what is enjoyable identified three main areas: working as a team, contact with patients and seeing the results of their work. Working as a team was said to be an important part of the job, enabling staff to work more effectively(L) and for a longer time than would normally be possible in a high stress area such as oncology(C). Working within a team was said to provide staff with a feeling of being supported by others: "The unit looks after its staff"(A). Informants spoke of feeling positive about working in the team, knowing there was support available to help deal with stressful aspects of the job(D). Informants described their work with patients as challenging(J) and enjoyable(K). The company of children, as well as interaction which allows for the development of a trusting relationship were identified as important and enjoyable aspects of working in oncology. Patient contact was said to be what made an otherwise stressful job bearable(E). The third area identified by informants as enjoyable for staff is in seeing the results of their work. Helping the child both physically and emotionally was said to be a satisfying and rewarding part of the job. Examples provided by informants included: helping the child to relax by reducing their level of anxiety(D); looking after a terminally ill child in the best way available(H); and helping the child to achieve greater normality(I).

What is difficult or stressful for staff

Oncology is not an easy area to work in(K), with underlying issues, (the most obvious being death) to cope with(I). The work is "emotionally quite draining"(K) and "uses up a lot of energy"(E). The effect of working in the unit was described by one informant in the following statement: "I'm probably a less light-hearted person than before I started the job"(H). The impact of working in the unit may even extend beyond the work environment. As one informant reported, "it's difficult not to take the job home"(E). Several informants reported experiencing difficulties in connection with the perceptions which other staff or parents have about their role. The chaplain spoke of difficulties relating to how parents perceived the role as "someone who represents no hope". The chaplain described the reactions of some parents towards her as reflecting an attitude of fear or uncertainty: "[Some parents think] if the chaplain comes, things must be grim." As a result of "inevitably upsetting some people", the chaplain said she was faced, in some cases, with having to "undo" such misperceptions. The school teacher reported difficulties with other staff (particularly nursing staff) whom she saw as judging her role in terms of how much she achieves with the children. The teacher said that some staff tend to evaluate the role on the basis of their own perceptions of what is important for the child. Academic work, for example, may be considered by some staff as more important than providing opportunities for the child to be enjoyably occupied. She stressed, however, that this was not a very common perception. The occupational therapist reported an area of difficulty as "misunderstandings about her role by other staff: "Consultants [who] don't really understand the role" and nursing staff who see occupational

therapy as "only playing with children." A consequence of such perceptions or misunderstandings, according to the occupational therapist, is that she "never gets formal referrals" from consultants and has "difficulty getting psychiatric referrals." The occupational therapist's view was confirmed by one informant who admitted to being confused about whether the role involved "getting children back to [normality]" or whether there was "a lot of psyche work to be done"(F). Nursing comments reflected difficulties experienced by them in terms of their image. One informant spoke of nurses having a "bad-guy image" if, when children are non-compliant in treatment or when parents do not take an active role in the child's treatment, nurses have to force the child(E).

A second area identified by informants as stressful or difficult is related to the emotional effects of working with the child and family. One informant identified the initial period of diagnosis and the implications of the diagnosis for the child as difficult: "Watching a child adjust to a diagnosis and knowing what they are going to go through"(L). Another informant spoke of working with children who are very ill as a result of illness and treatment as stressful, "knowing how awful they must feel"(I). Working with children can be difficult for staff when, for example, staff have to deal with a diversity of patients(E), or "a lot of new cases"(D). Inherent in working with children for some, is the difficulty of "getting to know the child and what might happen"(E). Other informants spoke of difficulties associated with the role such as "finding a balance between doing the job and being compassionate" and the challenge of being "patient and caring all the time...no matter what the child is like"(K).

Working with certain families can be stressful or difficult for staff. Families who are "struggling to adjust" require a lot of time and attention from staff(C). Family reactions to the illness such as guilt and anger can affect staff in terms of the extent to which parents are involved in the child's treatment, as well as the quality of the relationship between parents and staff. One informant spoke of the demands on staff who work in oncology to be "ever mindful and sensitive" of others (K).

A third area of difficulty or stress as identified by informants is the issue of terminal illness and the implications for staff who "have got to know the family and there is no hope left"(C). One informant reported the changeover from treatment to palliative care as "often more difficult for doctors than for the parents and child"(H) The impact of the death of a child on the unit as a whole was described as "incredible" but inevitable: "Sad times and good times go hand in hand here"(M). Staff reactions to the death of a child vary, according to informants' comments. Some informants said they were shocked by an "unexpected death" but otherwise "not particularly affected"(F), finding it "reasonably easy to continue working"(F). One informant reported that "dealing with the highs and lows [of cure and death]" was stressful, despite "having to carry on as a professional(D).

One implication for staff involved in an area of work which is identified as difficult or stressful is the need to be able to deal with any problems which arise from the work. Informants were asked to comment on how they dealt with stressful or difficult aspects of the work. Some informants said they dealt with problems by talking with other staff – professional

colleagues within the same discipline, nurses on the ward, at psychosocial meetings and with their supervisor. Some informants said they dealt with issues by discussing with partners, or by "being with the family"(H). One informant spoke of "not dealing with problems very well" (J) and others said they had not had to face "any major issues" in their work(L). One informant said she felt she could approach the social worker in the unit if she recognised a need for professional help(L). Although the need for a formal support system for staff was recognised(F), at the time of interview, none of the informants was aware of an existing system (apart from a unit meeting every three months). One informant outlined previous attempts at organising staff support but all were said to have "failed"(F). The most recent attempt was being prepared by the chaplain (at the time of interview) with the purpose of providing support for staff following the death of a child.(F)

Issues in addressing the psychosocial needs of the patient and family

The patient

The needs of the child are more effectively addressed when staff develop both an understanding of and relationship with the child. Lack of communication by the child was identified by several informants as having an impact on the ability of staff to gain an understanding of the child. Children tend to keep the meaning of the illness to themselves(K) and it is not always easy for staff to "pick up how they understand what's going on"(J). Children who are very ill and older children (over 10) were said to be particularly uncommunicative. With very ill children, according to one informant, "it's not easy to know what's going on"(I)

and older children (particularly boys) "don't say very much"(C) or "only talk to someone they feel comfortable with"(M). The development of a relationship with the child was said to be influenced by the amount of time required to get to know the child and family(L). According to one informant, "it's not that often you get to know the child that well"(D). The ability of staff to get to know the child is also affected by the individual child's reaction to staff: "The reactions of others [to staff] is linked to personality"(H) and by the attitude of the child. Withdrawn children, for example, were said to be difficult to motivate and are difficult for others to cope with(M). Some children develop a negative ("anti-everything") attitude and "make it very obvious that they don't want to be [involved in anything]"(K). In some cases limitations within the roles of team members can influence the development of a relationship. The doctor, nurses and the dietician all spoke of limitations on their time and not being able to "sit down and talk much with the child"(H)(J)(L). Psychosocial staff, some of whom work part-time in the unit, were said to be "busy and stressed"(I). The patient load(D) and the diversity of patients(E), identified as stressful aspects of the job, are additional factors which have an impact on the development of a relationship with the child and on the extent to which the psychosocial needs of the patient are met: "A lot of [children] seem to need one to one and there are not enough hours in the day"(D).

The family

One of the main reasons for addressing the psychosocial needs of the family, as indicated by informants' comments, is related to the impact of family coping on the child. Analysis of the data revealed three areas of

difficulty in relation to addressing the psychosocial needs of the family and which appear to be influenced by the following: parents' awareness of their own needs; parental reactions and the role of parents in treatment; and the availability and effectiveness of existing support services for parents.

In some cases, parents were said to have little awareness of their own needs. Parents can become "so enmeshed" in the care of the child that they "fail to notice their own needs"(D). Recognition of emotional needs is not a high priority for some parents who are more focussed on meeting the medical needs of the child. As a consequence, the emotional needs of both the parents and family are often overlooked(M). Informants who commented on this area stressed the importance of parents acknowledging their own "needs and rights" to look after themselves(D) as well as recognising the needs of the rest of the family(M). Parental reactions can be detrimental for the child and the child's treatment: "really uptight parents can be difficult"(F). Parents who are struggling to adjust"(C) were said to need a lot of time to come to terms with things(M). Emotional reactions such as guilt, anger and denial can influence the ability of parents to be involved in their child's treatment. One informant referred to the expectations which are placed on parents by staff to take responsibility in the child's treatment: "parents can accept but it's hard for them to take responsibility"(J). Some parents were said to "opt out" of involvement in the child's treatment "because they don't want to play the heavy"(E) or because they don't want to push [the child] when it will cause a struggle"(J). Parents who are identified as experiencing problems are referred to the appropriate team member as

soon as possible for psychosocial intervention(J). According to one informant, however, "the impact [of diagnosis] on the parent may not be picked up"(I). Another informant reported that even though identification of families "who are going to have problems" is the aim of staff, it is not always possible "to get in early to prevent them"(A). The extent to which the psychosocial needs of parents are addressed was also said to depend on the skills and training of the team members who work with the family: "social workers are not adequately trained for marriage counselling, which is what we need"(F) and on the level of understanding and awareness by staff of what the family is going through: "it would be helpful if nurses had more understanding"(C). In addition to services provided by staff in the unit, parents have access to a parent support group. According to one informant, the majority of parents who are involved in the group are those whose child has ended treatment and those with the greatest need (child in treatment) are not(D). Lack of involvement in other support groups which the unit has previously established to address the needs of parents was said to be due to the parents' inability to "leave their children to look after themselves"(D).

The terminally ill child and the family

A major difficulty in addressing the psychosocial needs of the terminally ill child and the family relates to the issue of communication. Lack of communication about death and dying was identified as having an impact on child and family coping and on the ability of staff who work with the family to address their psychosocial needs. Talking about death was said to be difficult because the subject of death "is often taboo in society"(C) and "all struggle to deal with it"(A). Informants' comments,

however, suggest that being able to talk openly about death helps both the child and family by reducing anxiety and fear as well as increasing the possibility of acceptance of death. Reasons given for lack of communication in children who are terminally ill were that some children are either unable to express themselves(D) or they choose not to communicate. Children who choose not to communicate were said to do so because they only talk to "someone they feel comfortable with" or they communicate only when they perceive that others are ready or able to talk(M). In some cases, children were said to be protective of others and avoid communication in an attempt to "protect the parent in their grief"(C). In other cases, the anxiety experienced by the parent may be "picked up" by the child who senses the parent's inability to cope and avoids communication(D). Lack of communication in parents was said to be due to reactions such as fear and anxiety, to the inability of parents to accept the child is terminally ill or to a desire to protect the child(M). Difficulties for staff arise when the child is not told they are dying and parents "refuse to allow discussion with the child"(K). If children are not told, one informant said, staff have to respect the parents' wishes not to tell(M) although this makes working with the child and family more difficult: "It's far easier to work with a family that is open"(D). Nursing staff were said to face difficulties such as "worrying [they] might say the wrong thing" and having to "sense how much involvement parents want [them] to have"(E)

5. Staff perceptions and evaluation of art and art therapy in paediatric oncology

The role of art in the paediatric oncology unit

Informants' comments relating to the role of art with paediatric cancer patients identified three ways in which art is currently used: as a diversion, as a therapeutic intervention and as a way of gaining increased understanding of the child.

Diversional activities such as art are recognised as being important on the ward(E). Nursing staff in particular are "conscious of the need for diversional therapy"(J). Involvement in activities was said to help the child "focus less on problems" by providing a distraction from such things as "needles and procedures"(E). In the use of art as a therapeutic intervention, both the children's activities coordinator and the occupational therapist said they used art to help the child express and communicate issues which arise as a result of the experience of being ill. In the use of art to gain understanding of the child, children's involvement in art was said to provide staff with opportunities to gain insight into how children are responding emotionally and developmentally (F). Both the artwork itself and observation of the child involved in art was said to provide information about how the child is coping (F). Informants' perceptions of the extent to which children are involved in art activities varied. One informant reported that "a lot of children are involved in art a lot of the time (H). Other perceptions suggested a lack of awareness of children's involvement: "I haven't got

much idea, I'm only aware of children being given paints etc."(I). One informant's perception was that there was minimal involvement in art on the ward : "My perception is that children don't do much art work here"(C).

Several informants spoke of using art as part of their work with children on the ward. The occupational therapist, the children's activities coordinators, the teacher's aide and out-patient volunteers were identified as using art in their work. Other informants who said they had at some time used art or craft with children include the social worker and a clinical nurse. The occupational therapist described the use of art as "facilitating the expression and communication of feelings for the child", as well as "getting an insight into where they're at". Art was said to have a cathartic role for the child, providing a means for children to "express and talk about their fears". The occupational therapist said that she does not try and interpret children's drawings: "I try and get them to talk about it". The use of art by the children's activities coordinator was said to be mainly diversional, although "what was intended as diversional can turn therapeutic". The CAC reported using art with children whom she feels "have a need to express". Although aware of the child's expression of concerns in art ("if a child is feeling bad then naturally the picture will express this"), the CAC said she "never gets kids to draw to see where they are at". Children are encouraged to express themselves freely, allowing them "to do things their way". The CAC said she offers activities which facilitate the child's expression according to their individual needs, for example, tearing paper for *collage* as a way of expressing frustration; finger painting to encourage a sense of freedom in a restricted

environment; group activities to provide opportunities for social interaction. Another children's activities coordinator reported using art with children for pleasure: "I don't look for anything." Her comments on the use of art in her role as CAC related to difficulties in getting children motivated and involved in art activities: "they are much more into videos". More than art and craft activities, the CAC uses story-telling a "as a craft" in ways similar to the use of art at both therapeutic and diversional levels: "it calms the child and takes the child's mind off things". The use of art by the teacher's aide was described as "product-focussed". Children were said to benefit from these sessions by having opportunities to be enjoyably occupied, by having control over what they create and by experiencing a sense of achievement in creating a product. The outpatients' area in the unit is staffed by volunteers who offer art and craft activities for children attending the outpatients' clinic. One informant reported the value of this service as providing a relaxed atmosphere in which children can participate spontaneously in activities which they enjoy and which acts as a diversion from the purpose of the visit, which may be that "they're going to have a needle"(M). The social worker reported having used art with children: "I used to ask the child to draw their family" while interviewing the family. The drawings were said to have revealed information about the child's perceptions of issues related to the illness such as the impact of the illness on the child and family. One of the clinical nurses interviewed spoke of having been involved in doing craft with children but with a change in her role she spends less time with the child at this level of involvement. The nurse commented that "it would be wonderful" if nurses had more time to spend with children in this way.

The value of art in paediatric oncology

Involvement in art

Informants' comments as to whether involvement in art is appropriate or beneficial for the child indicate that most informants consider art to be both appropriate and beneficial in helping to meet the psychosocial needs of children with cancer: "Art is very valuable"(M) and "of great benefit"(G). Moreover, according to one informant, "there is a great need for children to do art"(B). Involvement in art as more than a diversion was said to be appropriate anytime(F). The benefit of art for another informant was reported as mainly diversional: "It passes the time more than anything else"(H). The main benefits were said to be in addressing the normal needs of children (eg. the need for communication and expression, control, creativity and a sense of purpose); in addressing specific issues (eg. hospitalisation, separation and difficulties in communication); and in increasing staff awareness of how children are coping. Most responses in the area of the value of art for the child focussed on the ability of art to facilitate the child's expression and communication. Art was said "to encourage children to talk about certain things"(I). One informant stressed the importance of the child being able to "speak through art" about what they are feeling(K). This was said to have the added benefit of increasing awareness of what might be worrying the child for both staff and parents(I).

Art as a therapeutic intervention

Informants were asked to comment on the use of art as a therapeutic intervention, distinguishing this from the use of art as a diversion. Out of

a total of thirteen people interviewed, nine informants said they could see benefits in using art as a therapeutic intervention, such as providing opportunities for the child's expression and communication of concerns. Of the remaining four, one informant said she "would be interested to see how it works"(L), two said they didn't know enough about it and one expressed concern for how it would be used. Art as a therapeutic intervention was said to be appropriate for school-age children, adolescents, siblings and parents. Older boys were identified as a particular group that would benefit from a non-verbal medium such as art because, as one informant explained, "the way we work here is to ask how the child is feeling" and this group was said to have difficulty in expressing their feelings verbally(C). For parents, the use of art as an avenue for the expression of "pent-up feelings and frustrations" was said to be appropriate and beneficial(B). The use of art as a therapeutic intervention was said to be beneficial for all patients "from diagnosis on"(M) or "halfway through treatment"(F). Specific situations in which patients would benefit were identified as: in relation to treatment and procedures(I), in the prevention of stress(E), in general play(F) and for children in the laminar flow(C). The use of art in crisis situations (eg. diagnosis, relapse and terminal illness), as well as being of benefit to the child, was also said to be appropriate "as a way of knowing what's going on for the child"(M). For the terminally ill child, involvement in art would provide the child with opportunities for self-expression "without having to verbalise"(K). The artwork itself would provide the parents "with some remembrance of the child"(K):

The use of art therapy in paediatric oncology

The level of understanding and experience of art therapy among staff

Table 5 lists informants' responses to the question: What is your understanding of art therapy?

Using art as a form of therapy (helping the child express and communicate(I)

Providing opportunities for self-expression through the use
of art(M)(C)(D)(A)

Facilitating the communication of problems(L)

Facilitating expression in ways other than verbally(K)

To gain insight into where the child is at(A)

To find out meaning(F)

As interpretation(J)(L)(F)

As a diagnostic tool(J)

Table 5. Informants' Definitions of Art Therapy

Informants were asked what experience, if any, they had of art therapy.

While not all responses related specifically to art therapy, most reflected

an awareness of, or experience with, the use of art as more than diversional (eg. as a form of spontaneous expression, as interpretation, as symbolic representation). Table 6 lists informants' responses in the area of awareness or experience of the use of art as a therapeutic intervention, or art therapy.

Familiarity with children's artwork in working with children(A)(B) [eg. expression of emotion through the use of colour]

Attendance at a presentation and discussion of children's artwork within the hospital(G)(M) [eg. artwork of children in the burns unit; artwork of paediatric cancer patients]

Participation in an art therapy workshop(G)(J) [eg. art therapy in palliative care]

Awareness of the use of art with patients in other areas of the hospital(L) [eg. using art to help child communicate problems]

Literature on the artwork of physically ill children (F)(J)(M) [eg. common themes in the artwork of terminally ill children]

Table 6. Informants' Awareness or Experience of Art as a Therapeutic Intervention or Art Therapy

Although many informants were not confident in saying that they had a

good understanding of what art therapy was, most spoke with greater certainty about what they understood as the therapeutic use of art. Similarly with the area of experience of art therapy. More informants were able to give examples of the use of art for therapeutic rather than diversional purposes than were able to say they had experience of art therapy.

The place of art therapy in oncology

Informants' comments on the use of art therapy in oncology indicated a relatively high level of interest in seeing a service which offers art therapy to children on the ward. Six of the thirteen informants said that art therapy was, for example, valuable(G) or had potential(C). Two of these informants reported that art therapy "is [currently] not used enough"(F)(G). Although some staff were said to use art therapeutically, people who work in this area were said to need the proper training and skills in interpretation, guidance and in "creating alternatives"(F). One informant spoke of art therapy as "an important tool" and the role of the art therapist as "bringing in other skills" and "working closely with other [staff]"(A). The role of the art therapist was defined as "a professional with specialised knowledge and training in the area, with interpretation and communication skills" who would work in conjunction with psychosocial, medical and nursing staff, providing "more insight" to the team(C). The skills of the art therapist as identified by informants would also include: knowledge of the child's cognitive and developmental level(F); ability to assess the appropriateness of art therapy for the individual child(I); ability to get to know the child well enough to help(K); and the ability to draw the child out and get him or her to express

things(I).

Concerns relating to the practice of art therapy in oncology

One informant expressed concern for the number of services that are currently offered in the unit (occupational therapy, social work, children's activities services) and the effect of adding yet another: "Are we offering too many services?"(D). A second concern relates to where art therapy would fit in at an administrative level. Occupational therapy was identified as the area that is traditionally associated with the use of art in the hospital. For this reason it was suggested that an occupational therapist using art therapy would be the most practical way to include art therapy as a service on the ward(D). A third area of concern is the need for time in order to assess the value of art therapy in the unit. The problem was said to be that anyone conducting a study with children on the ward does not know who, or how long they have since the patient population varies so much(G). If the service is to be effective, the position would need to be full-time but "there may not be enough work"(D). Working on a sessional basis was seen by some to be problematic because staff have to be available when the need arises(D) and because working part-time restricts the development of a relationship with the child: "It's difficult to work with a child [once a week] unless skilled and able to get to know the child"(I). One informant commented on "the need to get to know the child and family before you can step in with a new experience" and in order for a new service to be effective: "For anything new to work, it needs to be given a fair go...before the therapy part works"(D).

Chapter Five: Discussion

The following discussion of the data is presented in three parts. Part one is a summary of the data outlining the experience of cancer for the child and family, identifying major issues and areas of need, and how the child and family cope. A composite picture of the experience of cancer for the child and family is presented, which is based on a compilation of the data relating to this area. Part two is concerned with evaluating the effectiveness of psychosocial services in addressing the psychosocial needs of children diagnosed with cancer. This part of the discussion is based on data which identifies (a) the psychosocial needs of the child and how these needs are addressed and (b) interrelating factors which have an impact on the extent to which psychosocial needs are met. Part three considers the role of art therapy in paediatric oncology on the basis of informants' perceptions of the role of art, art as a therapeutic intervention and art therapy in paediatric oncology.

(1) The experience of childhood cancer

Data relating to the impact of cancer on the child and family, the identification of issues facing the child and family, and how the child and family cope with the experience of illness were used to form the following composite picture. While not all informants commented on the same aspects of the experience or made the same observations about a particular aspect, each response is taken as a valid comment which contributes to the overall understanding of the experience of cancer for

the child and family.

A diagnosis of childhood cancer has an impact on the whole family. Living with a child who has cancer is a stressful experience which creates major disruptions to family life. Reduced social interaction, increased financial pressure, relationship problems between parents and the impact on siblings when the ill child becomes the focus of attention, are some of the issues facing the family. Children with cancer are faced with a range of issues in relation to the overall experience of illness. Childhood coping is related to the following broad areas: the life-threatening nature of the illness; the long-term nature of the illness; disruptions to life-style; and treatment and procedures.

Impact and coping: parents

The impact of a diagnosis of childhood cancer for parents and how parents cope, is partly influenced by the meaning which the illness has for them. Cancer is typically associated with a high rate of death and parents often expect, on receiving the diagnosis, that their child will die. Family adjustment to the illness varies and each family "develops differently" throughout the course of the illness. A range of emotional responses may confront parents at diagnosis: shock, fear, confusion, anger, guilt and self-blame. Some families adapt and "settle down with [the] routine" of treatment, while others "struggle to adjust". Fathers cope less well generally than mothers because they tend to have less input in the child's treatment, have less available time to spend with the child, and receive less emotional support. With the death of a child, parental

coping is related to the ability of parents to "work through" the experience. As with adjustment to illness, parental coping with a diagnosis of terminal illness for the child varies for each family. Parents who cope better with the death of their child are those who are "able to see something positive" in the experience, such as the end to the child's suffering. Overall, family coping appears to be influenced by two main factors: the extent to which parents are aware of and able to meet their own needs and the availability and effectiveness of psychosocial support.

Impact and coping: the child

Despite the life-threatening nature of the illness, children with cancer are sometimes able to "continue life almost normally". The experience of cancer can have a maturing effect on the child, increasing the child's level of sensitivity and awareness. Children with cancer are faced with a variety of issues throughout the course of the illness. The most commonly experienced areas of difficulty are in relation to treatment and procedures, hospitalisation, physical changes as a result of treatment, and terminal illness.

The treatment of cancer is long-term, ranging from six months to three years, depending on the type of cancer. At least one period of hospitalisation is required, as well as regular treatment as an outpatient. Treatment and procedures can have unpleasant and distressing side-effects for the child, including pain, nausea and vomiting, stress, anxiety and fear. Behavioural reactions of children experiencing problems in relation to treatment and procedures can include non-compliance with

treatment, anger and aggression toward others, lack of communication and withdrawal.

Hospitalisation entails a loss of routine, loss of personal space and lack of control over the environment. For younger children (under seven), emotional problems experienced in relation to separation from the family and the familiar home environment can lead to behavioural problems and discipline issues for parents. Older children may be more affected by disruptions to home, school and social life, and the inevitable loss of freedom and increased dependence on others.

Physical changes as a result of illness and treatment, such as hair loss, changing body shape and the effects of surgery, have emotional consequences for the child, particularly older children and adolescents. Children who feel self-conscious about their appearance may become withdrawn or depressed, they may be unwilling to participate in normal childhood activities, they may avoid contact with others and refuse to return to school.

The impact of terminal illness and how the child copes is inextricably bound up with the reactions of others and the interactions between the terminally ill child, the family and staff. Issues for the child include the personal meaning of the illness, the child's perceptions about death, and the ability of the child to communicate with others. Some children react to the knowledge that they are dying with fear, while others are more accepting. Differences in how children react are in part attributable to the reactions of others, the level of parental acceptance of the diagnosis, the

attitudes of others towards death and dying, the willingness or ability to talk about death, and the level of involvement of others with the child.

Two views emerging from the data reflect differing perspectives on how children cope with cancer. One view holds that children cope well and that it is rare for children to experience problems. A second view suggests that children with cancer face many difficult issues and that it is not uncommon for children to have difficulty in coping. The main factors influencing children's coping are: (i) the age and developmental level of the child; (ii) the level of family support; and (iii) the level of psychosocial support.

(i) The age and developmental level of the child

Younger children (up to six or seven) appear to cope better with illness and treatment than older children and adolescents. One explanation is that older children and adolescents have greater understanding of the illness and its implications. Older children, however, are able to communicate in a way that is more readily understood by adults (i.e. verbally), as compared to younger children, whose experience of illness is more difficult to understand and interpret. This is perhaps also the case for children diagnosed with a terminal illness - the younger the child, the less problems experienced in coping, due, in part, to the child's developmental level and cognitive understanding of his or her condition.

(ii) The level of family support

How parents cope, the level of emotional support they provide the child and the role of parents in treatment all have a strong influence on how the child copes. Offering emotional support, treating the child normally, encouraging communication and supporting staff in the child's treatment are important factors in helping the child to cope. Informants' comments on parental coping highlight the problems experienced by parents and consequently, by children. Children are perceptive of the reactions of parents, such as shock, fear, confusion and anxiety, and are aware when parents are not coping. Parents who experience problems in coping are less likely to be able to provide the child with emotional support, with the result that children may in turn feel confused, anxious, afraid or guilty. The following areas were identified as problematic in terms of the impact of parental coping on the child's ability to cope: parenting styles, attitudes of parents to staff and treatment, and terminal illness.

Parents of children with cancer were said, in some cases, to be overprotective or overindulgent of the child. This is in contrast to the team's belief that children with cancer should be treated normally and encouraged to participate in normal, age-appropriate activities. Deviations from this were seen as leading to behaviour problems in children, creating further problems for parents and more demands on staff and services. The role of parents in the child's treatment has an influence on the ability of the child to cope with the difficult and distressing aspects of treatment and procedures. Although parental support is valuable in helping the child comply with treatment, some

parents find it difficult to support staff in ensuring the child complies with all aspects of treatment if, for example, they witness the child experiencing stress, anxiety, fear or pain. Parental attitudes may thus compound the difficulties facing staff in administering treatment. Some parents were said to convey to the child a negative and antagonistic attitude of staff: the "bad guys" who inflict pain on their child. As a result, the child is more likely to experience problems in relation to coping with treatment and procedures. How children cope with a diagnosis of terminal illness is linked to the attitudes of others about death as well as to the ability of others to talk about it. Encouraging communication with the child is a valuable means of helping the child to cope. Problems in communication may occur, however, when parents are unable to accept the child is terminally ill, when they avoid telling the child in an attempt to protect the child, or when they keep a distance from the child because of fear or anxiety. A terminally ill child can be denied opportunities to talk openly about death because parents prevent staff from telling the child they are terminally ill. Parents who experience problems in these areas are likely, therefore, to experience difficulties in offering the child the level of emotional support required in order to come to terms with the inevitability of death.

(iii) The level of psychosocial support

Addressing the psychosocial needs of the child and family is recognised as an integral part of the child's overall treatment for cancer. A range of services is available in helping the child cope with the experience of illness, by minimising the trauma of serious illness and normalising the

experience as much as possible. Psychosocial services available include diversion, education, counselling and therapeutic intervention. Although these services do help the child to cope, the actual extent to which psychosocial services are able to address the needs of the child, is influenced by many factors. These factors are discussed in part two, which is concerned with evaluating the effectiveness of psychosocial services in paediatric oncology.

(2) Addressing the psychosocial needs of paediatric cancer patients: an assessment of psychosocial services

The psychosocial needs of the child and how these needs are addressed.

The main needs of the child with cancer were defined as normality, control, communication and emotional support. Children cope better when they are able to continue life as normally as possible. Participation in normal, age-appropriate activities provides the child with ongoing routine, structure and opportunities for social interaction. School-age children and adolescents are encouraged to return to school as soon as possible or, if hospitalised, to participate in ward activities or the hospital school. Education and counselling help the child to cope by providing information and emotional support in relation to the illness and treatment. Involvement in play addresses many of the younger child's psychosocial needs, providing a diversion, opportunities to feel in control

and a means to make sense of the experience of illness. All children need outlets for the expression of feelings experienced in relation to the illness, such as anxiety, fear, confusion, anger, sadness and depression. Many informants expressed the importance of communication for the child. Children were said to cope better when they are able to communicate.

In addressing both medical and psychosocial needs, the unit emphasises a team approach. All staff are aware of the impact of cancer on the child and family and the potential for the development of problems. Prevention, assessment for the development of problems and referral for intervention on identification of problems are the main components of the psychosocial treatment model. Psychosocial services are available throughout the entire treatment period, from initial diagnosis to whatever outcome (cure, long-term survival, or death). Psychosocial services available to the child and family consist broadly of diversionary activities, education and counselling, psychotherapeutic intervention, and support groups and social activities. The most widely accessed services for the child appear to be diversionary activities, education and counselling. Diversionary activities for children in hospital are seen as playing an important role as both a distraction and as involving children in normal childhood activities. Education and counselling is provided from diagnosis on, both as a form of preparation (educating about the illness and treatment) and emotional support (eg. counselling for issues such as hair loss; at crisis points, such as relapse and terminal illness,). Psychotherapeutic interventions include play sessions in the play room, preparation for procedures, referrals to the occupational therapist for

behaviour-problem children and referrals outside the unit, such as to psychiatry. These interventions may occur spontaneously (eg. play activities with a therapeutic focus), are scheduled on a weekly basis (eg. assessment for the development of problems), provided as required (eg. preparing a child for a medical procedure) or a referral is made via the team (eg. to psychiatry). Psychotherapeutic interventions address such issues as stress in children in relation to medical procedures (eg. medical play, story-telling); children with disruptive behaviour (eg. therapeutic play and art); and psychological problems associated with treatment (eg. hypnotherapy). Support groups, social activities and camps are organised regularly for both the child and family and provide a means for increased emotional support through the sharing of experiences related to a diagnosis of cancer in the family. Support groups are aimed at helping to relieve the sense of anxiety and isolation which commonly occur for all members of the family. Sharing with others in the same situation can help to increase the family's understanding and acceptance of, as well as the ability to cope with, the overall experience of cancer.

Evaluation of psychosocial services for paediatric cancer patients.

Analysis of the data reveals that for younger children (under nine), a diagnosis of cancer appears to have less psychological impact and fewer problems are experienced by the child throughout the treatment period. Psychosocial problems in younger children are commonly addressed by involving the child in both diversional and therapeutic play. Children up to the age of ten engage more spontaneously in play activities, using play for enjoyment as well as to work through emotional issues. Identifying

and addressing the problems of younger children in this way is perhaps more straightforward and successful than is the case with older children and adolescents. Older children are more affected by a diagnosis of cancer. They understand more, and are more aware of the implications of a serious illness. Missing school, restricted activity and changes in appearance all have a greater impact on this age group, as compared to younger children. The development of self-identity, the increasing importance of the peer group and a growing need for independence is often interfered with by a forced dependence on others and a lack of control over illness and treatment. Psychosocial services available to this age group are geared towards normalising the experience of illness as much as possible (for example, diversionary activities and continued schooling) as well as offering emotional support to help the child and adolescent cope with the many issues arising from the illness (physical changes, alienation from peers, returning to school etc.). Overall, psychosocial services appear to be more effective for younger children up to the age of nine or ten. Existing services do not appear to be as effective for older school-age children and adolescents, who were identified as "the biggest problem group" in terms of both the impact of cancer and addressing their psychosocial needs. The extent to which psychosocial services are able to meet the needs of all paediatric cancer patients is dependent on many factors. Analysis of the data identified three broad, interrelating categories which appear to have an impact on the effectiveness of psychosocial services in helping the child to cope: (i) limitations of individual psychosocial services; (ii) assessment of coping by staff; and (iii) staff issues: work-related stress and team functioning.

(i) Limitations of individual psychosocial services

The following psychosocial services were perceived by some informants as limited in the extent to which they address the psychosocial needs of children with cancer: diversionary activities for older children and adolescents, the hospital school; referrals for psychosocial intervention; and referrals to psychiatry.

Diversionary activities

Although participation in diversionary activities is recognised as important for the child, this area of psychosocial services does not cater well for older children and adolescents. Concern was expressed at the amount of time spent by some children in activities such as television, video and video games. Over-participation may be an indication of a lack of suitable alternatives for this age group, although engaging older children and adolescents in other activities was said to be difficult. The most obvious concern is the potential for the development of problems resulting from participation in passive and solitary activities which can have the effect of inhibiting the child's communication and social interaction and increasing the child's sense of alienation and withdrawal. Although diversionary activities are the most frequently accessed psychosocial service, they do not offer the child emotional support. Activities and interventions which have more of a therapeutic focus may be more effective in fulfilling the child's needs for communication, control and emotional support. An emphasis on meeting the normal needs of the child, one of the main purposes of diversional activities, does not allow for the acknowledgement of the child's inner needs, such

as the need to explore feelings or express strong emotion. To be diverted and to feel normal are not the only or most important needs of the child with cancer. Normalising the experience of cancer is only appropriate if the child is given adequate opportunities to express how abnormal the experience is.

Hospital school

Children in the hospital environment (both inpatients and outpatients) are encouraged to attend the hospital school and there is an expectation that children who are well enough will attend. Some of the problems identified with this area of psychosocial services include the attitudes of children and parents toward school and limitations of the teacher's role. The attitudes of children towards attending the hospital school influences the extent of the benefit of school activities for the child. Children who were said to be "anti-schooling" (as part of a general "anti-everything" attitude), may be limited by what they see as a forced participation in school. Parental attitudes and expectations in regard to their child's schooling can also influence the extent of benefit for the child. Although the child may not refuse to attend school (hospital school policy) parents do have a say in whether the child should attend or not. Decisions made by parents were said , in some cases, to have negative repercussions for the child. Children who do not attend may actually benefit from the structure which schooling provides, as well as an opportunity for socialisation and a sense of achievement in a supportive, child-centred environment. Conversely, parents who are over-anxious, or who have high expectations regarding the child's academic performance can create a stressful situation for the child. Limitations of the role of the teacher were said to involve having to balance the needs of

the individual child with the demands of the job. The role of the teacher in paediatric oncology is as much to provide the child with emotional support and opportunities for enjoyment, as it is to meet the child's academic needs.

Referrals for psychosocial intervention

Referrals made to psychosocial staff were seen to be limited in the extent to which they address the needs of the child. Psychosocial staff have commitments in other areas of the hospital, they are busy and therefore not always available, and they are limited in their skills and training. In addition, psychosocial staff do not provide other staff with enough feedback about what they do, or they "say they've done something" when other staff are unaware of any changes following a referral.

Referrals to psychiatry

Referrals to psychiatry are made when it is felt that the identified problem is of a sufficiently serious nature as to warrant attention by psychiatric staff. Such referrals are seen, however, as problematic, for reasons which included: the time required to obtain a referral, the perceptions of oncology staff that "nothing happens" following a referral, or because a referral to psychiatry is perceived as "threatening" by parents (some parents have refused to go). Comments by some informants indicate a belief, moreover, that referrals to psychiatry are inappropriate for issues relating to physical illness. Psychiatry, according to one informant, addresses problems of mental illness and is not for the "healthy psyches" of cancer patients and families.

(ii) Assessment of coping

Although, according to some informants, children cope well with illness and treatment, adjusting "because they have to", a range of emotional and behavioural reactions was noted, indicating that it is not uncommon for children to experience problems in coping. Similarly with children who are terminally ill, some informants perceived that children coped well: up to adolescence children have no fear of death and no perception of what they are losing, in contrast to the perceptions of other informants, that the period of dying for some children can be terrifying. Informants who believed that children cope well also expressed the view that psychosocial services were effective in helping children to adjust to the illness: it is rare for children to become fearful and withdrawn and staff intervene quickly when there is a need. Children were said to cope because their needs (normality, control, expression and communication, and emotional support) were adequately met by existing psychosocial services. This view was challenged by another group of informants who believe that children do not always cope well with illness and treatment and that their psychosocial needs are not well met. Reactions of children to illness and treatment such as treatment non-compliance, self-consciousness, low self-esteem, lack of motivation, withdrawal, depression and despair, as noted by informants, are indicative of behavioural and emotional problems requiring psychosocial intervention. The disparity in perceptions among informants raises an issue in regard to the assessment of coping by staff in the unit. It appears that there is no formal method of assessment, and coping is assessed on the basis of the behaviour and attitude of the child, his or her ability to

communicate and the level of family support. In the absence of a formal method of assessment of coping, differences in perceptions are inevitable. Staff have varying levels of psychosocial involvement with the child and family, determined by the individual role as well as, according to one informant, by personal choice. Some staff spend more time with the child and family than others. Nurses and doctors are busy and do not have time to sit down and talk with children to find out how they are going. Staff who are able to spend time talking or playing with children, thus encouraging the child's communication, become more familiar with the individual child and the kinds of issues which are experienced by children in general. These staff are also more likely to anticipate the issues and needs of children in future encounters with other children. This explanation is supported by the data which reveals that informants who perceived children as coping well with cancer were also those whose roles allowed them to spend the least amount of time with the child and family. Another explanation for differences in perceptions is that staff do not necessarily know when children are experiencing problems. Some children were said to be uncommunicative, through choice or because they experienced difficulties in communication. Withdrawn and uncommunicative children were identified as being "difficult" for staff because staff don't know what the child is experiencing, or how he or she feels about the illness. The ability of staff to recognise when a child is experiencing problems and to assess how well the child is coping is further influenced by such factors as the skills and training of staff, the ability of staff to develop a relationship with the child and family, the ability to encourage communication and the attitudes of staff in working with the child and family. These factors are discussed in the next section.

(iii) Staff issues

Work-related stress

Working in oncology can be stressful, challenging and emotionally draining for staff. Stressful aspects of the work which were identified by informants include : the patient load and the diversity of patients; difficulties in working with some children and families; and the area of terminal illness.

The number and diversity of patients restricts the amount of time staff have available to spend with individual children. Effectively addressing the psychosocial needs of children however, depends on getting to know the individual child, developing a relationship and building trust. In addition to time constraints and the impact on patient contact, staff face difficulties in relation to working with some children and families. Working with children who are uncommunicative, withdrawn or lacking in motivation is stressful for some staff because of the difficulty in developing a relationship with the child and knowing how to help. Some families who experience problems in coping are "needy and demanding" for staff. Working with such families requires a great deal of time and attention from psychosocial staff, who are limited in the extent to which they are able to address the needs of the family. A major issue for staff working with terminally ill children and families concerns the quality of the relationship between staff and the child and family. The difficulty of knowing what level of involvement staff should have with the child and family, how much emotional support is needed versus keeping a respectful distance, was said to be stressful for staff. A second, related issue

was identified as the difficulty in working with a terminally ill child when the parents do not want the child to be told he or she is terminally ill and staff are unable to discuss the subject of death with the child.

Team functioning

Despite an overt acknowledgement by many informants of the importance of working as a team, analysis of the data indicated a level of doubt in regard to its perceived effectiveness. Informants' responses in this area (team functioning and addressing psychosocial needs) suggest a kind of "split" between staff directly responsible for addressing the psychosocial needs of the child and family and staff whose role it is to refer for psychosocial intervention. The extent to which psychosocial staff are perceived to be effective in their roles is measured in part by such factors as: the availability of psychosocial staff, the skills and training of psychosocial staff and the level of understanding of psychosocial issues among medical and nursing staff.

There was general agreement among informants that psychosocial staff, who work part-in oncology, are busy and not always available to address an identified need. Psychosocial staff were also perceived by some informants as being under a certain amount of stress in relation to their role. Psychosocial staff work in other areas of the hospital, they have other duties and they are responsible and accountable to their own departments in addition to the oncology unit. One informant observed that psychosocial staff were not always available when needed and that nursing staff don't always refer a child or family for psychosocial intervention because "we can't always use them". The effectiveness of

interventions is limited in some cases by a perceived lack of skills and training of psychosocial staff. In certain areas psychosocial staff were said to lack the necessary skills and training, such as marriage counselling or were limited in what they are able to achieve. Occupational therapy and therapeutic play were seen as effective for "quick intervention" but at other times, these services are "not enough ... we sometimes need a psychologist". The level of understanding by medical and nursing staff of psychosocial issues and the roles of psychosocial staff influences the extent to which psychosocial services are perceived as effective. Medical and nursing staff were said in some cases to have limited understanding of the psychosocial issues confronting the child and family. One informant reported, however, that nurses do not receive enough feedback from psychosocial staff: "We gather information for them and they tell us nothing". Psychosocial meetings are seen as an important means for referring information and obtaining feedback i.e. linking psychosocial and medical/nursing staff. The latter group, however were seen as too busy, often, to attend the weekly meetings. Lack of understanding of the roles of some psychosocial staff by other team members was seen as problematic for some informants. Perceptions about the role of the occupational therapist, for example, identified a lack of understanding about the role: "Consultants don't really understand the role [and] it is difficult to get referrals". Examples of misperceptions of the same role were given as "only playing with children" and "only for behaviour problem children". It would appear from the data, therefore, that staff perceptions of and attitudes towards the roles of other team members may influence referrals for psychosocial intervention, that these perceptions and attitudes may have a strong impact on both the extent to

which psychosocial needs are addressed and ultimately, the overall effectiveness of psychosocial services in the unit.

(3) The role of art therapy in paediatric oncology

The place of art in paediatric oncology

Art is widely seen to be of value with the potential for addressing many of the psychosocial needs of patients, according to the responses of informants. Differences in perceptions on the actual extent of involvement by children in the unit suggests, however, that there is not a lot of integration of arts involvement and that the use of art as a part of treatment is not generally acknowledged.

The use of art in paediatric oncology was perceived as having two distinct purposes: diversionary and therapeutic. The use of art as a diversion was said to provide the child with something to do and to stop the child focussing on problems and the hospital environment. It is seen as offering enjoyment and as a means of passing the time. As a therapeutic activity, involvement in art helps to prevent anxiety and stress, encourages the expression and communication of issues, and allows others insight into how the child is coping. Children use art to express their feelings (eg. frustration and fear) and art activities facilitate and encourage the child's expression (eg. pounding clay, finger painting). The most commonly perceived use of art was as a diversion, available in the following areas of the unit: play room, school, outpatients' area and while in bed. Art activities in the play room were seen as primarily

diversional, but potentially therapeutic. Specific art activities are provided in some cases, to meet the perceived needs of the child, such as helping the child to express and communicate his or her concerns, encouraging the child's sense of freedom or control, and encouraging the child's social interaction. Both the artwork and observation of children engaged in art-making in this setting is seen as a valuable means of gaining insight into the child and staff use this information to assess how children are coping and identify any problems which may require further intervention by psychosocial staff. The occupational therapist was identified as the only member of staff who purposely used art as a therapeutic intervention, encouraging children to explore and express their concerns.

Although most informants perceived the current use of art as mainly diversional, most informants (nine out of thirteen) also expressed a belief in the value of art as a therapeutic intervention in paediatric oncology i.e. to help children express and communicate their concerns. The main benefits of art for paediatric cancer patients were listed as: addressing the normal needs of the child; addressing specific psychosocial issues; and understanding more about the child.

Engagement in art-making is a normal and familiar activity for children. Since normality is seen as important in helping children to cope, art is considered to be a valuable activity in paediatric oncology. Involvement in art is beneficial because it facilitates the child's communication and expression of concerns. Art is seen as a way of addressing specific issues for the child, such as hospitalisation and separation from parents,

difficulties in communication, lack of motivation and withdrawal. Children's involvement and expression in art was said to increase staff awareness and understanding of how children are coping at various stages of their illness. Art is both valuable and beneficial because it provides the child with a more natural and spontaneous means to communicate, enabling the child to "speak through art". The artwork produced encourages the child to talk and provides a means for gaining insight into what might be worrying the child.

Art therapy in paediatric oncology

Although informants generally found it difficult to define either the term or the practice of art therapy, most responses reflected some understanding and/or experience of the use of art as a therapeutic intervention. Art therapy was defined with reference to the psychosocial needs of paediatric cancer patients and the perceived relevance of art therapy in meeting these needs (a non-verbal therapy; facilitates self-expression in art, way of understanding the experience of others; involves diagnosis and interpretation). Six out of thirteen informants expressed a belief that art therapy would be valuable or had potential in paediatric oncology. Comments on the use of art therapy in paediatric oncology included: "Art therapy is an important tool" which is "not used enough". It offers an "alternative approach" to working with children. The main value of art therapy was described as encouraging the child's expression and communication through the use of a non-verbal medium which is familiar to children. Art therapy is seen as helpful in preventing the stress and trauma associated with cancer and in providing a means for

others (staff and parents) of finding out how the child is.

Although most informants were in favour of the therapeutic use of art, and several saw potential for art therapy, some concerns were expressed about introducing art therapy as an additional psychosocial service in paediatric oncology. These concerns largely reflect issues relating to the implementation of any new service and are discussed under the following areas: (i) the need for another psychosocial service, (ii) who should provide the service, (iii) the skills and training of the service provider and (iv) the effectiveness of a new service.

(i) The need for another psychosocial service

Oncology was described as "well-serviced", with better facilities for addressing psychosocial needs than most other departments in the hospital. A range of psychosocial services exist which are seen as appropriate and successful. The use of play, for example, fulfils the needs of the child at both diversional and therapeutic levels (easy to engage the child, facilitates the communication of underlying issues, way of getting close to the child and building trust). Concern was expressed at having too many services, and that it may be more appropriate to increase the availability of existing psychosocial services by creating full-time positions for current psychosocial staff. Oncology is well-serviced, according to one informant, "but how effective are the interventions" in addressing the needs of the child and family? Play may be appropriate and successful for some children (up to a certain age) but not for others (older children, especially boys; withdrawn; lack of motivation; seriously ill).

(ii) Who should provide the service?

Whether to incorporate art therapy practice into existing roles or employ a specialist art therapist was raised as an issue by informants. Some informants saw the potential for art therapy to be used as part of existing services, questioning whether it was necessary to have a qualification in art therapy in order to practise it. Since art is traditionally associated with occupational therapy in the hospital, some informants perceived that art therapy could be practised by an occupational therapist employed full-time in the unit. Other informants recognised art therapy as a specialist profession and stressed the need for a professional with training in art therapy, who would work in conjunction with psychosocial, medical and nursing staff, providing "more insight to the team". Art therapy, according to one informant, should be available in the unit as an adjunctive therapy on a regular basis. It would be inappropriate for existing staff to practice art therapy because they lack specialist training. Using art therapy, according to one informant, requires proper training, not just "picking up knowledge".

(iii) Skills and training of the art therapist

An art therapist employed to work in the paediatric oncology setting should have adequate and appropriate skills and training. A professional working in the area, according to informants, should be trained and skilled in several areas, such as assessment of clients for the appropriateness of art therapy; counselling ("What happens after the art work is produced?"); interpretation ("It's not as easy as looking at

something and saying this is what it means"); guiding the child; and creating alternative avenues of expression.

(iv) The effectiveness of a new service

Effectiveness, according to informants' responses, is influenced by such factors as time, the patient population and the attitudes of patients, as well as the availability, abilities and attitude of the therapist. The time needed for "something new to work", fluctuations in the patient population, and the attitude of some patients (eg. a lot don't want to be bothered; some are in pain; some are "anti-everything") were identified as factors influencing the effectiveness of art therapy in the paediatric oncology setting. In order for art therapy, or any other psychosocial service, to be effective, the art therapist must be available whenever the need arises. Ideally, the art therapist would be employed full-time, allowing time for the development of a relationship with children and making intervention easier. Despite recognition of the restrictions of working part-time in paediatric oncology (in regard to availability), however, one informant thought there may not be enough work for a full-time position. An effective service was said to depend on being able to "get to know the child and family". Developing a relationship with the child, helping to draw the child out and helping the child to express were described as important abilities of the therapist working with paediatric cancer patients. In addition to the above, the attitude of the art therapist was identified as an important factor in the extent to which the service is effective. Working in paediatric oncology requires a sensitivity to the needs and issues of children on the part of the therapist. Art therapy,

according to one informant, should not be too directed. Children need to have freedom in their art expression and should not have to explain what they do in art. Overall, an art therapist working in paediatric oncology needs to be aware of and sensitive to the many patient issues experienced as a result of the illness and treatment and how these may impact on the ability of art therapy to meet the psychosocial needs of paediatric cancer patients.

4. Summary

The above discussion of the data has focussed on the following broad areas, namely, the experience of childhood cancer for both the child and the family, the identification of psychosocial needs, evaluation of psychosocial services and the extent of their effectiveness, and an investigation of the role of art therapy as a psychosocial service in paediatric oncology. Most of the discussion has focussed on the first three areas, for two main reasons. Firstly, most of the data collected during the research process was concerned with these three areas and little, by comparison, on the area of art and art therapy. Secondly, the wealth of data compiled on these areas was such as to suggest that as much emphasis should be placed on identifying and exploring the similarities and differences in informants' perceptions in these areas, as on exploring the role of art therapy as a psychosocial service in paediatric oncology.

Exploring informants' perceptions of the experience of cancer for the child and the family provided valuable background information on what it is like for the child and family, what are some of the issues they face and

how the child and family cope. Overall, informants identified the experience of cancer as highly stressful requiring psychosocial intervention to help both the child and family cope throughout the experience of illness and treatment. The psychosocial needs of paediatric cancer patients and the family are addressed with an emphasis on a multidisciplinary team approach. A variety of psychosocial services are available to meet the child's needs for normality, expression and communication and emotional support. The actual extent to which children diagnosed with cancer are able to cope with the experience of illness and treatment is, however, dependent on the interrelationship of many factors.

An assessment of psychosocial services was indicated because of the identification by many informants of serious problems experienced by children diagnosed with cancer on the one hand, and because of differences in the perceptions of informants relating to the extent of child coping and the effectiveness of psychosocial services in helping children to cope, on the other. An interpretation of the data identified four main interrelating areas which appear to influence the impact which a diagnosis of cancer has on the child, as well as on how children are assessed regarding the impact of the illness and their psychosocial needs. The first area revealed specific problems facing children, such as difficulties in communication, lack of motivation, depression and despair. Specific groups of children were also identified (eg. older children and adolescents, terminally ill) in terms of both the problems facing these groups and difficulties in addressing their psychosocial needs. Difficulties in communication, a problem frequently identified for

paediatric cancer patients, were said to be a result of, for example, the tendency of children to keep the meaning of the illness to themselves, or of their need to feel comfortable with people before they will communicate. The second area concerns parental reactions, the ability of parents to cope and the impact of these on child coping. Most parents were said to be more concerned with meeting the medical needs of the child and less responsive to meeting the child's emotional needs. Parents who have difficulty coping were said to be less able to meet both their own and the child's emotional needs, with the possibility for children to distance themselves emotionally from parents, becoming withdrawn and uncommunicative. The third area concerns issues relating to psychosocial services. It is possible that the provision of a psychosocial service which emphasises diversionary activities as a means to address the normal needs of the child is not as effective in addressing other needs relating to the expression of the child's emotions, such as fear, anxiety, anger or depression. The fourth area, relating to staff issues, reveals areas of difficulty for staff, such as work-related stress, the perceived lack of understanding of psychosocial issues and psychosocial staff roles by medical and nursing staff, the lack of a formal support system for staff who work in oncology and the impact of these on the extent to which staff feel that the psychosocial needs of the child and family are able to be met.

The discussion of the data relating to informants' perceptions on art and art therapy reveals a commonly held view that art has an important role to play in meeting the psychosocial needs of paediatric cancer patients. Informants' responses indicated a belief that art was not widely used and

that the actual use of art in the unit was perceived as being mainly diversional. Several informants expressed a belief that the use of art as a therapeutic intervention would be a valuable way of addressing the needs of patients, siblings and possibly parents. Informants' responses to the use of art therapy in paediatric oncology reflected a relatively strong level of interest in seeing art therapy used in paediatric oncology. Lack of understanding and experience of art therapy as a profession (as opposed to the use of art as a therapeutic intervention) by informants, as well as the expression of concerns regarding the practice of art therapy in paediatric oncology, were indicated as major factors influencing the extent to which art therapy was perceived as being useful in paediatric oncology.

Chapter 6: Conclusions and Recommendations

Conclusions

The overall conclusion reached in this research is that art therapy in the paediatric oncology setting is feasible and could provide a service which is recognised by many oncology staff as necessary and valuable but which existing staff do not have time to fulfil (Walker, 1989). On the basis of both the research data and the literature on the use of art therapy with physically ill children in general and with paediatric cancer patients in particular, it would appear that art therapy would be a valuable addition to the range of psychosocial services currently available to paediatric cancer patients.

Art therapy in the medical setting

Art therapy in the medical setting is provided in recognition of the need for a psychotherapeutic service which addresses the psychological issues associated with physical illness. Art therapy with physically ill patients is valuable as a means for the expression and communication of the subjective experience of illness, allowing for the identification of concerns and the need for intervention to address these concerns. The literature on art and art therapy in the area of physical illness has demonstrated the usefulness of art therapy in addressing the psychosocial needs of physically, chronically or seriously ill patients. Involvement in art for physically ill children addresses the normal needs of hospitalised children

(Parish, 1986; Radziewicz & Schneider, 1992; Rollins, 1990; Romero, 1986) and the artwork of physically ill children allows for a clearer understanding of the child's experience of illness (Rae, 1991; Schwarz, 1978). Art therapy provides a means for addressing the many issues associated with physical illness, such as separation from the family, body image and fear and anxiety in regard to treatment (DiCowden, 1987; Geraghty, 1985; Oppenheim Cameron et al., 1984). Art therapy in the area of terminal illness allows for the expression of powerful emotions connected with dying (Bertoia & Allan, 1988) and art therapy in paediatric oncology provides opportunities for the expression of emotions and the exploration of areas of conflict in relation to a life-threatening illness (Councill, 1993; Sourkes, 1991; Walker, 1989).

Art therapy in paediatric oncology

Art therapy in paediatric oncology offers potential benefits at many levels: addressing the child's need for normality, helping the child to cope, increasing quality of life through the alleviation of emotional suffering and providing greater insight for others. Art therapy offers the child a non-threatening and non-verbal avenue for expression and communication and provides the therapist with a means for appreciating the child's view of the world. Art therapy with children is effective because children are attracted to the inherent qualities of art and the possibility for play. For older children, art therapy is an effective, alternative and indirect means for the exploration of issues, in addition to providing opportunities to explore the many creative and imaginative possibilities inherent in the art-making process.

Art therapy involves a process of art-making within a therapeutic framework. The child's expression in art is facilitated by the therapist, who encourages the child to represent his or her own individuality and personal experiences. Acknowledging the child's reality in this way, the therapist supports the child through a process of exploration and discovery, helping the child to develop a stronger sense of self and an increased capacity to cope. Art therapy allows for a greater understanding of the issues involved in cancer as they are perceived by the child. The artwork of children, because it reflects their emotional state, can illuminate areas that are little understood by others, such as the meaning of illness for the child, childhood stress, generalised anxiety and depression, the child's awareness of his or her terminal condition and attitudes towards death and dying.

Recommendations

(a) Integrating art therapy into the paediatric oncology setting

Introducing a new service into an already established environment involves consideration of many factors. The following areas were identified as relevant to the integration of art therapy as a psychosocial service in paediatric oncology: (i) Education about art therapy; (ii) Liaison with paediatric oncology staff; and (iii) Art therapy programme design.

(i) Education about art therapy

Given that art therapy is a relatively new profession and awareness of its

potential in the medical setting may be limited, it is important to provide those who work in this environment with information about art therapy. Administrators, heads of department, staff, patients and families all need to know enough about art therapy to feel comfortable with its place alongside existing psychosocial services. Education about art therapy might include the provision of both practical and theoretical information about how art therapy is used in similar settings, why art therapy is valuable in a given setting, what the art therapist does (as opposed to other professionals using art) and for whom art therapy is appropriate. Case study presentations by the art therapist working in paediatric oncology would be a valuable way of raising awareness of the appropriateness of art therapy with a particular population (eg. patients, parents, siblings, staff). An educational component also provides an opportunity for the art therapist to address the concerns of others (such as those previously identified) in regard to the practice of art therapy in paediatric oncology.

(ii) Liaison

Liaison might involve communication with staff who work in the paediatric oncology unit, both on an individual basis and as a team. Liaison serves a mutual purpose in that the art therapist learns from the team such things as how needs are identified and referred, and the team is made more aware of the role of art therapy in addressing the psychosocial needs of paediatric cancer patients. Liaison is an important part of establishing art therapy in this setting because of the need to address such issues as identifying those who would benefit from

involvement in art therapy (via, for example, an art therapy workshop, seminar, a needs assessment, client questionnaire etc.); when art therapy should be offered (at diagnosis, throughout treatment, as prevention, at crisis points etc.); how to involve clients in art therapy (outpatients, inpatients, family etc.); what form of art therapy should be offered (individual, group, family therapy etc.) and what system of referral would be used (eg. informal and formal referrals, via psychosocial meetings, direct referral from client etc.).

(iii) Art therapy programme design

An art therapy programme design would provide clear guidelines as to the nature and purpose of an art therapy service in paediatric oncology. (eg. routine screening, as prevention, at crisis points, throughout the treatment period). Art therapy could be used as an assessment tool (eg. to assess the impact of cancer and identify needs of specific groups), as a therapeutic intervention (eg. at crisis points, throughout the treatment period, as a preventive therapy, as a form of family therapy), or to explore areas which are not well understood (eg. childhood stress, generalised anxiety and depression, the meaning of illness for the child). A model art therapy programme would detail various aspects of an art therapy service, such as where to conduct art therapy sessions, materials needed, liaison with psychiatry, feedback to the team and evaluation of outcomes. From this basic structure, further needs and requirements in relation to an art therapy service would be identified and ongoing modifications could be made.

(b) Further research in art therapy in paediatric oncology

As with any psychosocial service available in the medical setting, art therapy will be limited in the extent to which it can address the psychosocial needs of the patient and the family. Further research in the use of art therapy in paediatric oncology would enable both a more focussed exploration of areas of need and the identification of areas of greatest need. The needs of the whole family, for example, might be addressed through the use of family art therapy, or art therapy may be used to increase staff understanding of the child's perceptions of illness at both physical and emotional levels. Although the purpose of this research was to assess the feasibility of art therapy to address the psychosocial needs of paediatric cancer patients in general, several, more specific issues emerged throughout the research process which, if investigated in greater depth, would make the case for the use of art therapy in the paediatric oncology setting even stronger.

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APPENDIX 1: Details of Research for Heads of Department

To: The Head of (Name of department)

RE: Art Therapy Research Project

TITLE: Art therapy in the paediatric oncology setting: the perceived usefulness of art therapy from the perspectives of staff in the oncology unit.

I am writing to inform you of a research project which will be conducted at (name of hospital) involving a selection of staff from the oncology unit. In order to undertake this study, the hospital's research and ethics sub-committee has stipulated that approval be obtained from the head of department of each area from which staff are selected for participation in the research. Participation in the study will involve an individual interview (one hour), an art therapy presentation seminar (one hour), a written report (one page) and a questionnaire (approximately 20 questions). The study will be conducted during staff working hours. If you agree to the participation of staff from your department in the study, would you please complete the attached form. Should you require any further information about this project, please contact me (telephone number).

APPENDIX II: Form of Disclosure and Informed Consent

Art therapy research project: art therapy in the paediatric oncology setting

This research project is designed as a thesis to be conducted in partial fulfilment of the requirements for the degree of Master of Arts (Art Therapy) at Edith Cowan University.

Purpose of the research project: the project will involve an exploration of perceptions regarding the usefulness of art therapy in addressing the psychosocial needs of paediatric cancer patients from the perspectives of staff in the oncology unit at a metropolitan children's hospital.

Procedures: the procedures to be followed in the conduct of the research project will involve individual participation in an interview and group participation in an art therapy presentation to be given by the researcher. In addition, informants will be asked to give written responses regarding the research topic in the form of a self-report and a questionnaire.

Rights of informants: participation in the research is voluntary and informants may choose to withdraw from the study at any time.

Confidentiality: every effort will be made to ensure informant confidentiality by the use of codes and pseudonyms in the final report.

Time commitment: participation in the research project for each informant will involve a total of approximately five hours over a period of approximately one month.

Benefits to informants: informants can expect to benefit from

participation in the study through an increased understanding of and knowledge about the use of art therapy in the paediatric oncology setting. A copy of the completed research will be made available to informants.

Any questions concerning the project entitled: Art therapy in the paediatric oncology setting can be directed to (name and telephone number of researcher).

APPENDIX III: Consent Form

Ihave read the information above and any questions I have asked have been answered to my satisfaction. I agree to participate in this activity, realising I may withdraw at any time.

I agree that the research data gathered for this study may be published provided I am not identifiable.

.....
Informant

.....
Date

.....
Researcher

.....
Date

APPENDIX IV : Interview Questions (Guide)

I. Professional background

- a. How long have you worked in this unit?
- b. What are your reasons for having chosen to work in this unit?
- c. How would you describe your role?
- d. What is the most enjoyable aspect of working in this unit?
- e. What is the least enjoyable aspect of working in this unit?

2. Patient information

- a. How would you describe the impact of cancer on the child/adolescent/
family?
- b. What are the psychosocial needs of paediatric cancer patients in relation
to the following: diagnosis; treatment; relapse; terminal phase?
- c. What services are available to meet the psychosocial needs of paediatric
cancer patients?
- d. To what extent do these services meet the psychosocial needs of
paediatric cancer patients?
- e. In what other ways could the psychosocial needs of paediatric cancer
patients be addressed?

3. Children's art and art therapy

- a. What is your experience with and understanding of the artwork of paediatric cancer patients?
- b. What benefits (if any) do you see for these children in drawing/painting/clay etc.?
- c. What is your understanding of art therapy?
- d. What is your opinion regarding the use of art therapy with paediatric cancer patients?

APPENDIX V: Age of the Child and Impact of Cancer

Infants (0 - 18 mths)

Immune from psychosocial impact
Integrate into treatment with few problems

Toddlers (18 mths - 3 yrs)

Behaviour reactions possible eg. enuresis

Preschool (3 - 5 yrs)

Some awareness of the severity of illness
Perceptive to parental reactions (eg.unhappiness)
Behavioural problems
Regression possible (eg. giving up walking)
Adjust to treatment
No long-term consequences for the future

School-age (6 - 7 yrs)

Few problems if able to communicate
about illness and treatment

(up to 9 yrs)

Greater understanding
Mature quickly

(10 - 12 yrs)

More preoccupied with illness and implications
Understand cancer as life-threatening
Lower pain threshold
Lack of communication

Adolescence (over 12 yrs)

Greatest impact of all age groups

Issues of adolescence (body image, emotional difficulties,
acceptance by peers)

Limited or lack of communication

APPENDIX VI: Informants' Perceptions of Coping

Children cope well

i. Adaptation

"they have to adapt so they do" (H)

"some children continue life almost normally" (M)

"many move between school and hospital easily" (H)

ii. Support

"some children bounce through...a lot of family support" (I)

"everyone can get through with quick intervention" (F)

"coping [is related to] being able to talk about treatment" (J)

Children have difficulty coping

i. Treatments and Procedures

children can be resistant, difficult, stressed, fearful, withdrawn, angry and aggressive towards others

ii. Body Image

self-conscious, shy, embarrassed in public
school refusal

"hair loss is the biggest impact of all" (M)

iii. Illness and Hospitalisation

Anger : "when a child is waiting for treatment to finish" (M)

Lack of motivation: "a lot of children don't want to do anything" (I)

"lethargic, staying in bed" (K)

"some give up, can't be bothered trying" (I)

Lack of communication: "some children haven't spoken to parents for weeks" (D)

Depression and despair: "a lot get depressed...part of the process of
diagnosis, treatment and hospitalisation" (I)
"some get into a spiral leading down, don't
feel like doing things" (I)
"anti-school work...anti-everything" (K)