Chapter 1

Introduction
Introduction

Approximately 72,000 patients were diagnosed with cancer in the Netherlands in 2003. Incidence is expected to rise by 30% over the next 15 years mainly due to ageing of the population. The age adjusted cancer incidence for males is 448 per 100,000 and for females 350 per 100,000. One third of all people in the Netherlands will be diagnosed with cancer during his or her lifetime. The incidence of cancer increases with age, and only nine percent is diagnosed below the age of 45 years (1). The prevalence of cancer is 65% for women and 35% for men in the child-rearing age group of 35-55 years (2). Breast cancer is the most common cancer in female patients aged 30-59 years, testicular cancer in men aged 30-45 years, and lung cancer in men aged 45-59 years (1). Each year, 9,000 patients with children living in the home are diagnosed with cancer in the Netherlands (3).

Developments in diagnostic imaging with spiral computer tomography (CT), magnetic resonance (MR) imaging, positron emission tomography (PET) improved the non-invasive staging of cancer patients. Performing such diagnostic tests requires time, which means a longer time of uncertainty about the diagnosis and psychological stress for the patients and their family members.

The type of treatment a patient with cancer needs mainly depends on tumor type and stage of cancer. Patients diagnosed with localized malignancies are generally treated with local treatment (surgery and/or radiotherapy) and those diagnosed with systemic cancer with chemotherapy. Metastatic disease is often treated with systemic treatment such as chemotherapy, hormonal therapy, immunotherapy or a combination of these treatment modalities. Chemotherapy is increasingly applied also for primary tumors combined with radiation (e.g. head and neck tumors, cervical cancer) or as adjuvant treatment for tumors with unfavorable prognostic characteristics (such as regional lymph node involvement in breast cancer). Patients with cancer may suffer from acute and late side-effects of treatment. The treatment of cancer is generally intensive, and the short and long term outcome often unpredictable. The diagnosis of cancer and its treatment may affect not only the patients, but also the family members. Until now, psychosocial research was mainly focused on the patients, sometimes on their spouses, but research in children of cancer patients is limited. The present thesis will focus on the children of parents diagnosed with cancer.
Theoretical background: stress, trauma and family systems

Stress, stressor and trauma
Stressful life experiences pose a potential threat to the well-being and healthy development of children and adolescents. Stress in children has been defined as: “...any intrusion into children’s normal physical or psychosocial life experiences that acutely or chronically unbalances psychological equilibrium, threatens security or safety, or distorts physical or psychological growth/development and the psychological consequences of such intrusion or distortion”(4). The intrusion is the stressful event itself, the stressor(5). Such events may come from outside the person (such as the death of a grandparent) and from inside the person (such as emotions). Several characteristics of the stressor are found to be related to stress, such as the physical proximity of the event, the duration and intensity of the threat, and the controllability and predictability(6,7).
Some stressors are traumatic. The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) defines trauma as “a stressor involving direct personal experience of an event that involves actual or threatened death or serious injury, or other threat to one’s physical integrity; or witnessing an event that involves death, injury or a threat to the physical integrity of another person; or learning about an unexpected or violent death, serious harm, or threat of death or injury experienced by a family member or other close associate” (Criterion A)(8). Exposure to such a stressor is the first criterion for a posttraumatic stress disorder (PTSD). To meet criteria for PTSD, reactions have to include symptoms of three broad categories: re-experiencing (recurrent and intrusive distressing memories of the event), avoidance/numbing (e.g. avoidance of thoughts, feelings or conversations associated with the event, and diminished interest or participation in normal activities), and increased arousal (e.g. sleep difficulties, irritability, and angry outbursts)(8,9). PTSD in children often coincides with other emotional and behavioral problems, such as separation anxiety, anxiety, depression, somatic complaints, and cognitive problems(7,10,11).
One of the traumatic stressors a family may be confronted with is a serious or chronic illness in one of the family members, such as cancer in a parent.

Parental cancer: a stressor for children
The diagnosis and treatment of cancer may cause substantial distress for patients, and their family members, in particular because of the threat of losing a loved one and uncertainty about the future (e.g. (12,13)). An important difference between cancer and other major events is that cancer is an ongoing and not a discrete event(14). Parents and children experience a sequence of stress periods, beginning with the initial diagnosis of cancer and continuing throughout medical treatment to recovery. Some treatment regimens may cause more changes in family routines...
than others. For instance, family life may be more affected when the parent is repeatedly hospitalized for chemotherapy than when the parent is treated in an outpatient setting. As cancer patients are increasingly treated in outpatient settings, some children will also be confronted with acute visible side-effects of the parents’ treatment at home. Some children will face complications of their parents’ treatment or intensive care hospitalizations. In general, patients may be less able to undertake activities with their children, because of severe fatigue. After completion of treatment, patients are followed up for years. Many families suffer the continuing threat of a recurrence of disease and some actually experience recurrent illness. They have to go through the process of treatment again, realizing that prognosis of relapsed or metastatic disease is often dismal.

**Family systems theory**

Children are closely connected to the family system which has to adapt repeatedly to changing circumstances(15). A family system is a ‘complex, integrated whole’(16), wherein ‘individual family members have a continuous and reciprocal influence on each other’(17). Mothers, fathers and children influence each other both directly and indirectly(18). From a family system perspective, changes in the condition of one of the family members (such as depression) or in the patterns of relationships among family subsystems (such as the marital relationship or the parent-child relationship) may affect the functioning of the others. Furthermore, the emotional cohesion between family members, and the ability of families to adapt to change (adaptability) influences the functioning of all family members(19).

In the case of parental cancer, the parent with cancer, the spouse, and the children each may react in their own way to the illness. The way one family member deals with the illness may affect the functioning of the others. For example, children may have more difficulty to adapt to the illness when parents have more emotional problems(20-24).

The following research model, based on the family systems theory, has been used as a framework in this study to help examine the functioning of children, concurrently and over time. This model represents the stressor parental cancer, which may affect all family members. Individual characteristics of the parent with cancer, the spouse and the child(ren) may affect children’s well-being.
Content of the thesis

Children of parents diagnosed with cancer are considered to be at risk for psychosocial problems. The literature available on the subject is limited and shows contradictory results (25). Therefore, this thesis will address the following main research questions:

1) Are posttraumatic stress symptoms (PTSS) and emotional and behavioral problems prevalent in children of cancer patients?
2) To what extent do PTSS in children of cancer patients coincide with other emotional and behavioral problems?
3) Which characteristics of children, parents and the family are related to the prevalence of PTSS and emotional and behavioral problems in children of cancer patients?
In Chapter 2 studies published between 1980 and 2004 on the impact of parental cancer on children and the family are identified and reviewed. Chapter 3 contains a pilot study on the psychosocial consequences for children who have a parent with cancer, from the children’s as well as the parents’ perspective. Semi-structured interviews and standardized questionnaires were used to explore the prevalence of emotional and behavioral problems in children of cancer patients, and factors associated with such problems. Chapter 4 focuses on a cross-sectional study on the prevalence of PTSS and on the relationship between PTSS and emotional and behavioral problems in children of parents diagnosed with cancer 1 to 5 years prior to study entry. Relationships between children’s age and gender, the ill parent’s gender, children’s personality, children’s perception of the parent’s illness and illness related variables and PTSS are described. Chapter 5 presents a study on the quality of the communication between adolescents and parents in families of cancer patients. Open communication has often been advocated when a parent is diagnosed with cancer, because this would have a positive effect on the functioning of the children. This study examines whether adolescents who perceive good communication with their parents actually report fewer PTSS, and whether communication in families with cancer patients differs from that in families not confronted with cancer. Chapter 6 provides a study that first focuses on characteristics of parents with cancer and their spouses as predictors of PTSS, internalizing and externalizing problems in adolescent children using multilevel analyses. The second aim was to examine if siblings reported more alike problems than children of different families. Chapter 7 reports on the results of a longitudinal prospective study on PTSS in adolescent children of parents recently diagnosed with cancer. Furthermore, factors affecting PTSS, associations between PTSS and emotional, behavioral or cognitive problems, and concurrent and prospective effects of PTSS on child functioning are studied. In Chapter 8 the results of this thesis and methodological issues are discussed. In addition, implications for clinical practice and future research are considered. Chapter 9a, b, and c summarize the results of the studies in this thesis in English, Dutch and Frisian, respectively.
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Cancer Treatment Reviews 2004; 30: 683-694