CANCER IN ADOLESCENTS, THE SOCIAL DEVELOPMENTAL CHALLENGES IN IDENTITY FORMATION

A SYSTEMATIC LITERATURE REVIEW

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Dedication

This study is dedicated to one of the author’s mother the late Eunice Kahugu, for her love and support, you are always in my thoughts. To the second authors son Ngoh Emmanuel Anye.

To all the adolescent cancer patients and their families this is for you.
ACKNOWLEDGEMENTS

The authors of this study would like to express our gratitude and appreciation to God Almighty for the strength, favour and grace to complete this work. We would like to thank our supervisors Hannele Kauppila and Hannele Pietiläinen and Anitta Örn for the professional guidance and academic advises received for the completion of this work, your endless effort meant a lot to us. Also, our friends, teachers and the whole Lapland University fraternity thank you for your support throughout our study period.

One of the authors would like to thank her family, especially her father Paul Kahugu and grandmother Susan Wambura for their unconditional love and support.

The second author wishes to express her gratitude to her family, her father and mother, Mr & Mrs. Mbuh, sisters, Blanche & Barbara and her brother Nsoh Neville, for their love and support.
This study dealt with Cancer in adolescents, social developmental challenges in identity formation. The purpose of this study is to provide nursing students with information on how to care for cancer adolescent patients in practice. This study will help them in their work practice and in the future when they are nurses as they will know how to care for these adolescent cancer patients. This study tried to answer the question; what kinds of social developmental challenges do adolescents with cancer face? This study was based on qualitative research method and the authors chose systematic literature review for the collection of data. The collected data was further analyzed by content analysis method.

Childhood cancer is a chronic disease and experiencing cancer during adolescence presents unique difficulties like stress and coping issues, academic incompetence due to health problems and stress, anxiety, challenges in social life and esteem issues. A diagnosis of cancer during adolescence adds a significant stressor to this unique period of development. Controversy exists regarding whether cancer causes a major disruption to the achievement of developmental tasks and increased psychological morbidity. The following social developmental challenges in adolescents with cancer were obtained from this study, Relationships (family and peer), personal development (Identity development, confidence, and career path) and course of life.

The following Key words were used, Cancer (oncology), adolescents, Identity formation and social development.
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1 Introduction

Cancer is a class of diseases characterized by out-of-control cell growth. There are over 100 different types of cancer, and each is classified by the type of cell that is initially affected. (Wu, Chin, Haase & Chen 2009, 2358). Childhood cancer is a chronic disease and experiencing cancer during adolescence presents unique difficulties like stress and coping issues, academic incompetence due to health problems and stress, anxiety, challenges in social life and esteem issues. (Compas, Connor-Smith, Saltman, Thomsen & Wardsworth, 2001, 87). (Wallace, Harcourt, Rumsey & Foot, 2007, 1019). Studies have shown that 10–15% of children with cancer fail to complete their treatments because of poor adjustment during this treatment. (Yeh, Lin, Tsai, Lai & Ku ,1999, 193). Adolescents with cancer are reported to keep their anger to themselves, passively accept procedures, and have lingering fears about the treatments .(Yeh, 2001, 141).

A diagnosis of cancer during adolescence adds a significant stressor to this unique period of development. Controversy exists regarding whether cancer causes a major disruption to the achievement of developmental tasks and increased psychological morbidity. (Maguire, 2006, 136). Cancer in adolescents is considered a major stressor affecting development, and it raises a distinctive challenge for both adolescents and their families. (Abrams, Hazen & Penson, 2007, 622). The difficulties of these treatments negatively affect adolescents’ lives in several ways; causing physical problems (e.g. bone marrow suppression, nausea, vomiting, fatigue, pain and malnutrition). (Larouche & Chin-Peuckert, 2006, 200), psychological suffering (e.g. uncertainty, anxiety, depression, loss and physical changes). (Woodgate, 2006, 8). According to Larouche et al., 2006 & Abrams et al., 2007 Cancer in adolescent’s causes altered social functioning (e.g. disruptions in education and interpersonal relationships). Hence, knowing how adolescents cope with disease and treatments is fundamental to caring for them during a specific illness and developmental stage. (Vance & Eiser 2002, 5).

Adolescence is the period of development when a child becomes an adult. American Academy of paediatrics classified adolescence according to years from puberty to adulthood, which it may be divided into three stages: early adolescence, generally ages eleven to fourteen; middle adolescence, ages fifteen to seventeen; and late adolescence, ages eighteen to twenty-one. There are many tasks an adolescent achieves in their development to adulthood. These include developing independence
from their parents, developing relationships, and one of the most difficult, choosing a career path. The diagnosis of and treatment for cancer is a difficult time for individuals and their families, and is compounded by these challenges. To help adolescents cope effectively with their experiences of cancer, health professionals need insight into the challenges that these adolescents endure and an understanding of what resources each adolescent needs.

Adolescence is process of physical and psychosocial maturation and this study will mainly focus on adolescents aged between 11-21 years. Adolescent age is very crucial in everybody’s life because it is at this stage that one’s Identity is formed. Everything that happens at this stage affects who we become as adults in a big way. Motivation for this study came when one of the researchers thought she had cancer and the trauma associated with this feeling made us interested with this study. Also being young influenced us and we seek to understand the challenges adolescents with cancer go through. As nursing students this study is very important for us because it will help us understand what adolescents with cancer go through and it will make it easier for us to assist them and help them cope. This study will be useful for the society (their family, friends) as it will help them understand them better and educate them on how to handle them and treat them with normalcy so they do not feel secluded or different.

The aim of this study was to explore the social development challenges that cancer adolescent patients face and how it affects their identity. The purpose of this study is to provide nursing students with information on how to care for cancer adolescent patients in practice. Länsi-Pohjan District Hospital cancer polyclinic agreed to use this study to help nurses and nursing students in practice understand adolescent cancer patients and how to take care of them. There has been previous researches related to this topic and they tell that; Evidence suggests that a chronic illness may negatively influence identity formation. (Jacobson, Hauser, Milley, Wertlieb, Wolfsdorf, Herskowitz, Lavori, & Bliss, 1990, 511).
2. Cancer in Adolescent

Cancer is a term used for diseases in which abnormal cells divide without control and are able to invade other tissues. Cancer cells can spread to other parts of the body through the blood and lymph systems (National Cancer Institute).

An estimated 69,212 Adolescents and Young Adults (AYAs) ages 15–39 in the United States of America were diagnosed with cancer in 2011. This is about six times the number of cases diagnosed in children ages 0–14. The incidence of specific cancer types varies dramatically across the AYA age continuum. For example, leukaemia, lymphoma, testicular cancer (germ cell tumours), and thyroid cancer are the most common cancer types in younger AYAs (15–24 years old). By ages 25–39, breast cancer and melanoma comprise a growing share of cancers among AYAs.

The graph (Graph 1) below shows the common cancer types among adolescents and young adults with cancer.
Every year in Europe 15,000 children aged 0–14 years and 20,000 teenagers and young adults aged 15–24 years are diagnosed with cancer. (Ferlay, Bray, Shin, 2010, 2893).

Overall survival at 5 years continuously improved from 76.1% in 1999–2001 to 79.1% in 2005–2007. (Gatta, Botta, Rossi, 2014, 35). However, 6,000 young people in Europe still die of cancer.
each year despite best available treatments. No progress has been made for malignancies with the worst prognosis (brain tumours, neuroblastoma, sarcomas and acute myeloid leukaemia). Across Europe there are still major disparities in 5-year survival, for example Eastern Europe reports 10–20% lower survival rates. (Gatta et al., 2014, 35). Cancer remains the commonest disease causing death beyond the age of one year in Europe. It is estimated that 300,000–500,000 European citizens are survivors of a childhood cancer: 60% of them have at least one chronic health problem and 30% have severe long-term sequel. (Pritchard, Pieters, Reaman, 2013, 95). Increasing both cure rate and quality-of-cure (defined by presence and intensity of treatment complications in a long term survivor) for young people with cancer are the two goals for the next decade. The types of cancer occurring in this age group in Europe are similar to those observed in the rest of the world. (Pritchard, Kaatsch Stelianova, 2006, 2183).

Cancer treatment in adolescents is similar to that of adults and is often part of national and international research studies. The treatment may include chemotherapy, radiation therapy and or surgery. (Pizzo & Poplack, 2002), (Pinkerton, Plowman & Pieters, 2004), (Gibson & Evans, 1999), (Whelan, 2003, 2573). These treatment regimes are commonly known as protocols. Protocols are a guide for the type of treatment to be used. The main aim of treatment is to administer enough chemotherapy or radiation to cure the cancer while minimising effects of treatment. These effects can be debilitating and occasionally fatal. (Weiner & Cairo, 2002). The specific medical treatment for all cancers should follow the recommended protocols for that disease and is generally not age related. However, psychosocial aspects are care should be provided in a related manner. (Lewis, 1996, 887). Lewis identified a significant increase in long-term survival rates of patients when treatment was coordinated in a major children’s cancer hospital or unit. This is due to the specific oncology focus of the multi-disciplinary team and the supportive care facilities available. There is no equivalent data currently available on adolescents who have cancer; however it is likely that a similar increase in survival rates would apply in this age group if treatment is provided by a specialist multi-disciplinary team.
2. 1. Aim & purpose

The aim of a study is a description of exactly what issues the research tends to address. (Moule & Goodman, 2014, 79). A research proposals aims are statements that broadly point out what you hope to accomplish and desired outcomes from the research. Aims focus on long-term intended outcomes, your aspirations in reference to the research. They’re typically not numbered in the research proposal. Each aim may have several purposes associated with it. (Bryam & Bell, 2007). The aim of this study is to explore the social developmental challenges that cancer adolescent patients face and how it affects their identity.

The purpose of a study is the same as the meaning of the study and strives to answer the research question(s). (Moule & Goodman, 2014, 79). Purpose layout how you plan to accomplish your aims, purpose are focused and practical. They tend to pinpoint the research’s immediate effects. They include a list of practical steps and tasks you are going to take to meet your aims. Both aims and purpose should be brief and concise and should be interrelated. (Bryam & Bell, 2007). The purpose of this study is to provide nursing students with information on how to care for cancer adolescent patients in practice.
3. Definition of Adolescence

W.H.O defines adolescence as a period in human growth and development that occurs after childhood and before adulthood, from age ten to nineteen. It represents one of the critical transitions in the life span and is characterized by a tremendous pace in growth and change that is second only to that of infancy.

American Academy of paediatrics classified adolescence according to years from puberty to adulthood, which it may be divided into three stages: early adolescence, generally ages eleven to fourteen; middle adolescence, ages fifteen to seventeen; and late adolescence, ages eighteen to twenty-one. (Neinstein, 2002, 35). According to Arnett (2000, 55), Adolescence and young adulthood are the development stages marked by rapid changes in cognitive and emotional growth. Adolescence is also the period of developmental transition between childhood and adulthood, involving multiple physical, intellectual, personality, and social developmental changes (Cleveland Clinic Children's). The developmental stage of adolescence is described as a transition between childhood and adulthood.

American cancer society 2011, state that, during the critical developmental transition from childhood to adulthood, older adolescents and young adults in particular have typical concerns with establishing identity, developing a positive body image and sexual identity, separating from parents, increasing involvement with peers and dating, and beginning to make decisions about careers or employment, higher education and/or family. (Cancer society 2011, 2289). Cognitive development is also a key feature of adolescence. According to the information processing approach to cognitive development, children and adolescents develop their ability to process information gradually building their abilities of memory and thinking .(Santrock, 2004). Adolescents are able to process information differently from children because of their structural and functional capacity. The adolescent’s brain has developed so that it is physically able to function at a higher level and they are able to utilise this higher function. (Seifert & Hoffnung, 2000). Throughout adolescence these abilities improve. Adolescence cannot conceptualise as much information in early adolescence as
in late adolescence. An adolescent’s ability to process information may impact on their ability to cope with their situation.
This study will focus on adolescents between 11-21 years old because according to American cancer society this stage is important in establishing identity concerns and identity formation is very crucial for this study.
4. Social development in adolescence

Adolescence is the transitional period between late childhood and the beginning of adulthood and marks the beginning of the reproductive lifespan in humans. Adolescence involves sexual maturity in terms of hormones and physical development of the body and is also characterised by an increase in the complexity of group interactions and thus social behaviour. (Lerner & Steinberg, 2004).

Anecdotal evidence and self-report data suggest that children seem to become progressively self-conscious and concerned with other people opinions as they go through puberty and the period of adolescence. (Steinberg, 2005, 69). The psychosocial context of adolescents is markedly different to that of children and adults. Relationships with peers, family and society go through distinct changes during this time. Adolescents begin to assert more autonomous control over their decisions, emotions and actions and they start to disengage from parental control. At the same time the school context involves an intense socialisation process during which adolescents become increasingly aware of the perspectives of classmates, teachers and other societal influences.

According to Kids matter (Australian primary school mental health initiative), social development involves learning the values, knowledge and skills that enable children to relate to others effectively and to contribute in positive ways to family, school and the community. This kind of learning is passed on to children directly by those who care for and teach them, as well as indirectly through social relationships within the family or with friends, and through children’s participation. Through their relationships with others and their growing awareness of social values and expectations, children build a sense of who they are and the social roles available to them. As children develop socially, they both respond to the influences around them and play an active part in shaping their relationship. (Kids matter.edu, Read; 25.02.2015).
Diagram 1. Influences of social development

The above Diagram 1 shows how different social groups affect the development of a child socially and individually. According to the diagram, family, school and peers play a major role in the development of children as they struggle to develop their own identity. Through their relationships and connections with others, children build a sense of who they are and where they fit in the social world.
4.1. Social Developmental Challenges among adolescents.

A large part of an adolescent’s socialisation usually occurs in school, and this can be disrupted by a diagnosis of cancer. (Hampson, 2000, 21). Adolescence and young adulthood are developmental stages marked by rapid changes in cognitive and emotional growth. (Arnett, 2000, 469). Accordingly, cancer related issues such as premature confrontation with mortality, changes in physical appearance, increased dependence on parents, disruptions in social life and school/employment because of treatment, loss of reproductive capacity and health related concerns about the future may be particularly distressing for adolescents and young adults. (Cancer 2011, 2289).

Adolescence and young adulthood are periods of development particularly susceptible to disturbance. Adolescents and young adults make the transition from childhood into adulthood as they develop physically, psychologically, sexually, and socially. Independence from family, identity formation, focus on appearance and self-image, development of intimate relationships, adjustment to pubertal growth, as well as establishing future goals are all hallmarks of adolescence and young adulthood. (Gavaghan, Roach, 1987, 203).

4.1.1 Loss of confidence

Throughout their experience with cancer, adolescents experience a sense of losing their confidence because of the many challenges of having cancer, especially the fact that they cannot control the situations. During adolescence, a large portion of self-esteem is derived from sexual identity. Cancer, during this developmental period, may present certain challenges in establishing a positive Sexual identity. Obstacles in accessing sexual-health knowledge, difficulties in interpersonal relationships, and body image concerns may be hurdles that adolescents and young adults with
cancer confront in pursuit of sexual health, which may, in turn, hamper the development of positive self-esteem. (Kyngäs, Mikkonen, Nousiainen, Ryttilahti, Seppänen, Vaattovaara, Jämsä, 2000, 6).

The adolescent with cancer has to deal with physical changes as a result of their treatment in addition to the usual developmental changes, which can lead to the adolescent with cancer having trouble maintaining a positive body image (Carr-Gregg & White, 1987, 496). Hair loss, weight gain, “moon-faced” appearance and acne are some of the issues which may have negative impact on an adolescent with cancer when they are developing self-esteem, body image and sexual identity.

4.1.2 Social isolation

Cancer adolescent patients feel isolated or desire isolation from their peers. In an interview conducted by (Yeh, 2001, 141). To Taiwanese cancer adolescent patients this was evident. Most of the participants missed school often (some up to a year) due to repeated hospitalization. Patients expressed not caring about friends or peers at school however, at the same time their behaviour showed a hunger for friendship with peers.

A large part of an adolescent’s socialisation usually occurs in school, and this can be disrupted by a diagnosis of cancer. (Hampson, 2000, 21). Isolation from peers and treatment-related cognitive impairments can hinder the development of social skills required for the initiation of relationships. (Newby, Brown, Pawletko, Gold & Whitt 2009, 113). Social support refers to the perceived availability of friend’s family to help a person cope with stress. For children with cancer, social support also contributes to personality and social development. Social support is a multi-dimensional construct that involves the type of relationship, the type of frequency of supportive behaviour and the quality of support. (Lackner, Benesch, Schargel, Kerbl & Schwinger 2000, 750). Social isolation is a very big challenge that this adolescent’s face and having friends with the same condition could ease the situation.

4.1.3 Family relationships
According to the family-system perspective, the functioning of parents and the family influences the functioning of children and vice versa. In several studies on childhood cancer, parental distress was found to be correlated with the emotional functioning of children, but it’s different to determine the direction of the correlation. (Patenaude, Kupst, 2005, 9). Most investigators report that the functioning of families experiencing childhood cancer is within normal limits. (Velika, Booth, Smith, Brown, Lynch, 2004, 714), although some indicate that the parents of survivors are overly protective and that they are more rigid and less flexible than are the parents of children who do not have disease. (Houtzager, Oort, Hoekstra-Weebers, Caron, Grootenhuis, Last, 2004, 591).

Family dynamics can be compromised when an adolescent is diagnosed with cancer because it causes changes in the roles of family members. The adolescent may not be able to fulfil their usual roles and siblings may need to assume aspects of adult roles. (Robert, Turney & Knowles, 1998, 3). The family’s finances may be disrupted due to the loss of one parent’s income because they are required to care for the adolescent. The loss of income can affect the family’s lifestyle. The change in family dynamics can also impact on the adolescents siblings and they may be at a higher risk of psychosocial problems. (Robert et al., 1998, 3).

4.1.4 Peer Relationship

Across studies of children with varying forms of cancer and treatments, recent evidence suggests that experiences with childhood cancer treatment may have implication for children's social functioning and peer relationships. Survivors of childhood cancer have been found to engage in less than half the number of social activities as their peers. (Pendley, Dahlquish, & Dreyer, 1997, 29). They are also rated by parents as having poorer social competence and are seen by peers as sick, fatigued, and absent from school. (Kullgreen, Morris, Morris, & Krawiecki, 2003, 1), (Schultz, Ness, Whitton, Recklitis, Zebrack, Robison, Mertens, 2007, 3649). Survivors of childhood cancer have also been identified by peers, teachers, and parents as more socially isolated and withdrawn than their classmates or sibling. (Schultz et al., 2007, 3649), and they describe themselves as feeling isolated from their peers. (Vannatta, Garstein, short, Noll, 1998, 279).
There is also evidence that the friendship quality of survivors of childhood cancer may be different than their peers. Survivors rate themselves as having fewer close and confiding relationships when compared to children who have never had cancer. (Sloper, Larcombe, & Charlton, 1994, 163). They are also less likely to be seen by peers as having best friends. (Reiter-purtill, Vannatta, Gerhardt, Correll, Noll, 2003, 467), are chosen by peers less often as a best friend and receive fewer friendship nominations from classmates. (Vannatta, et al., 1998, 279). They are also less likely to use friends as confidents. (Barrera, Shaw, Speechley, Maunsell, & Pogany, 2005, 1751). When followed into adulthood, their friendships are shorter in duration and characterized by less intimacy than those of their peers. (Mackie, Hill, Konydryn & McNally, 2000, 1310).

4.1.4 Career path

Nowadays, about 80% of children with cancer survive the disease, but 40% of survivors have late adverse effects. (Oeffinger, Mertens, Sklar, Kawashima, Hudson, Meadows, 2006, 1572). With the increase in survival from childhood cancer, research has been growingly focused on the educational and professional achievements of childhood cancer survivors. (De Boer, Verbeek, & Van Dijk, 2009, 163). In addition, many studies have underlined a lower educational or occupational achievement of female survivors compared to male survivors. (Kirchhoff, Krull, Ness, Park, Oeffinger, Hudson, Leisenring, 2011, 3033). (Lancashire, Frobishet, Reulen, Winter, Glaser, Hawkins, 2010, 254). Studies have shown that young survivors could report a negative impact of cancer on their vocational aspirations. (Servitzoglou, Papadatou, Tsiantis, & Vasilatou, 2008, 29), lower professional expectation or less concrete plans for the future. (Boman & Bodegard, 2004, 354) or a change in their career plans resulting from cancer. (Servitzoglou et al., 2008, 29).

Besides the poorer academic performances due to frequent absenteeism from school during periods of illness and hospitalization, it might delay opportunities to explore personal and occupational interests. Moreover, poor health in childhood might influence educational aspirations, resulting in a projection in long-term educational goals. Fear of recurrence of health conditions induced by treatment toxicities might influence survivors in their planning about education plans, and, therefore, might negatively affect their educational and occupational achievement. (Boman et al., 2004, 354)
4.1.5. Identity formation

Components of identity include a sense of personal continuity and of uniqueness from other people. In addition to carving out a personal identity based on the need for uniqueness, people also acquire a social identity based on their membership in various groups—familial, ethnic, occupational, and others. These group identities, in addition to satisfying the need for affiliation, help people define themselves in the eyes of both others and themselves. (Josselson & Ruthelen, 1987).

According to Erik Erickson the process of ‘liking oneself’ takes place across the lifespan and is influenced by the internal beliefs, emotions and social experience. Before adolescents can consider whether they like themselves, they have to discover who they are. Thus, Identity formation (‘who am I’) becomes one of the most significant developmental tasks during this age period. (Erick Erickson, 1998).

Adolescents typically undergo four hierarchical stages of Identity formation:

1. Identity diffusion in which they test out various identities through trial and error (the experimental stage)
2. Moratorium in which they enter an ‘identity crisis’ (‘I can’t figure out who I am’) 
3. Foreclosure in which they adopt someone else’s identity (‘I am just like my friend’)
4. Identity achievement in which identity is achieved through a conscious decision-making process. (‘This is who I am because these are my beliefs and how I want to be’)

To arrive at this last stage of identity achievement, adolescents need to feel emotionally independent enough from their parents so that they base their chosen ‘self’ on a decision-making process that is uniquely their own. (Marcia, 1966, 551). This is a process in which they need to reconcile the past ‘self’ of the childhood and the imagined future ‘self’ of the adulthood. They carry out this reconciliation through an interactive process with their social environment in order to achieve their present identity. (Erik Erickson, 1998)

Identity development is a key aspect of healthy growth and development for adolescents and young adults. Successful achievement of this milestone requires healthy peer relationships, as identity
development occurs within the context of social interaction. (Arnette, 2000, 467). However, isolation and alienation are commonly reported among adolescents and young adults cancer patients, as they often miss out on experiences that their peers are enjoying such as dating, leaving home and establishing independence, going to college, pursuing gainful employment, getting married or having children. (Zebrack, Hamilton, Wilder-Smith, 2009, 375-385).

4.1.6. Informational requirements

Adolescents with cancer require information about their diagnosis, treatment and side effects to feel control over their situation. They have similar informational needs as adult cancer patients due to their cognitive development. Adolescents understand abstract and complex concepts and feel empowered if they are given the opportunity to have access to their own records, or allowed to choose options if they exist. (Hampson, 2000,21). Empowering patients through support and information helps them to develop improved coping mechanisms. (Whyte & Smith, 1997,137). Timing and delivery methods can affect the way an adolescent is able to understand information given to them. An awareness of how the adolescent is feeling is important because if they are feeling unwell or is in an unfamiliar environment, they may find it difficult to understand, or be overwhelmed by the difficult concepts. They may feel pressured and therefore not absorb the information given to them (Woodgate, 1998, 57). Therefore, adolescents require timely information provided when they are able to absorb it.

5. Description of the Research

The research task;

What kind of social developmental challenges do adolescents with cancer face?
5.1 Methodology

The study was designed using a qualitative approach characterised by inductive reasoning which according to (Moule and Goodman, 2009, 33), start with the details of an experience or observation of something and using these to develop a general understanding of phenomena. The aim of qualitative research is to have a holistic view and to see the whole picture of a particular situation. (Moule & Goodman, 2009, 206). The authors used a systematic review literature as the method of choice because it allows retrieval, critical appraisal, and summary of all evidence based knowledge on a subject matter. Systemic literature review is a literature review focused on research question that tries to identify, appraise, select and synthesize all high quality research evidence relevant to that question. Literature review is the selection of available documents (both published and unpublished) on the topic, which contains information, ideas, data and evidence written from a particular standpoint to fulfill certain aims or express certain views on the nature of topics, and how it is to be investigated and the effective evaluation these documents in relation to the research being proposed. (Hart, 2003,3). Whereas narrative reviews entails provision of qualitative summary on individual studies or research evidence. Typically systematic review article usually focus on a single specific question, without attempting to provide an overview of the topic. Also it focuses on previously defined inclusion and exclusion criteria. (Sim & Wright, 2000, 283). The intention was to extract relevant information systematically from the publications. Since this research was to provide relevant information about the social developmental challenges adolescent with cancer face from a social point of view, hence a systematic literature review was considered.

A systematic literature review was chosen because it helps to focus on a research topic and by so doing enables the progressive narrowing that turns a topic into a practical research project. It also tries to deliberate avoidance of selection bias as it adapted to a transparent and scientific approach. Systematic literature review, also determines the consistencies and generalization of scientific findings across populations. (Chapman, 2009). Those research articles published on the social developmental challenges; identity formation adolescents with cancer face comprise the primary data collected and analyzed in this research. The stages of data processing were literature search, data collection, data screening, data extraction and data analysis or synthesis.
5.2 Literature Search

A literature search is “a systematic and explicit approach for identification, retrieval and bibliographic management of independent studies drawn from published sources from the purpose of discovering information on a topic, synthesizing conclusion and identifying areas for future studies and developing guideline for clinical practice” (Cahn, Auston & Selden, 1992). Electronic databases such as EBSCO, ELSEVIER Science Direct, Pubmed and JBI CONNECT were search through trials with the key words or subjects terms, cancer, adolescent, identity formation, and social development. These key words were typed into databases in a combination of pairs and triplets to retrieve relevant articles using BOOLEAN operators “AND” or “OR” substitute word such as oncology were used in place of cancer. The motive was to ensure that many relevant articles that had similar purposes to our research were found. Citations and abstract that correspond with our inclusion and exclusion criteria were identified, recorded and retrieved. Materials were also gathered through e-books, e-journals and online articles which mainly were free and of full text. After the thorough search, the English results were read through to determine those which were scientific and evidence-based to be considered enough for implementing for this research.

5.3 Data Screening

Data screening was carried out by assessing the titles, abstract, and citations of potential relevant articles against predetermined criteria for inclusion and exclusion criteria. The full text of studies whose titles and purpose were not convincing enough to support the decision making as regards to their eligibility and relevance were obtained and assessed against the criteria for inclusion and exclusion. Researchers relate each article as relevant purpose of the study, irrelevant or not clear for decision making. Relevant articles were those which have all the criteria for inclusion and exclusion
in the table I below. Disagreements with regard to selected articles were resolve through discussion and further consultation.

<table>
<thead>
<tr>
<th>INCLUSION CRITERIA</th>
<th>EXCLUSION CRITERIA</th>
</tr>
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<tbody>
<tr>
<td>Publication date; between 2000-2015</td>
<td>Articles published before 2000</td>
</tr>
<tr>
<td>Language; English articles only</td>
<td>Other languages except English</td>
</tr>
<tr>
<td>Full text articles</td>
<td>Non-full text Articles</td>
</tr>
<tr>
<td>Title of the article; is it related to the topic cancer in adolescents, the social developmental challenges in identity formation.</td>
<td>Non-related topic</td>
</tr>
<tr>
<td>Relevant purpose of the study</td>
<td>Irrelevant purpose of study</td>
</tr>
</tbody>
</table>

**Inclusion and exclusion table 1**

The table 1 above shows the inclusion and exclusion criteria used to collect data during research for this study.

**5.4 Data Collection**

Data collection is a systematic approach to gathering of information from a variety of sources to get a complete and accurate picture of an area of interest. (Rouse, 2013)

Data collected involves the gathering of useful information for the purpose of supporting decision making based on facts. A total of 2,921 articles were identified altogether through literature and manual search and were later screened for eligibility and relevance against define inclusion and exclusion criteria. 2,915 were rejected after thorough search and the purpose of the remaining 63 were obtained and examined, out of which 57 were further discarded and 6 were finally selected and identified as relevant and were used in this research.
Data collection table 2

<table>
<thead>
<tr>
<th></th>
<th>Initial search</th>
<th>Thorough search</th>
<th>Relevant</th>
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<td>9</td>
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5.5 Data Extraction

According to (Sandelowski & Barroso, 2003) data extraction is an attempt to reduce a complex, messy, context-laden and qualification-resistant reality to a matrix of categories and number. Data extraction is the process by which researchers collect relevant information about their study characteristics and findings from data sources.

Data extraction were those which consisted information needed for the purpose of description and for analysis later in the systematic literature review. The year of publication, names of authors, purpose of the study, research method, general finding and significant findings were extracted from the articles that involved the eligibility criteria. The reason for data extraction “is to describe the research in general, to enable later synthesis, to extract the findings from each research in a coherent manner, and to extract information to enable quality appraisal, so that findings can be interpreted. This need to be done in a way as to required minimal references to the original papers at the data synthesis stages,” (Social institute for Excellence, 2006).

The Data extraction table can be found in the appendices.

5.6 Data Analysis
Qualitative content analysis was used for the data collected in this research. According to (Hsieh & Shannon 2005, 1278), qualitative content analysis is a research method used for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns. Qualitative analysis is any qualitative data reduction and effort that makes sense which takes a volume of qualitative material and attempts to identify core consistencies and meanings. (Patton, 2002, 453). According to the principle of conducting a qualitative content analysis, data were analyzed based on the research objective of this study (deductive) and also from the significant findings after series of readings and interpretations of the raw data (inductive). The analysis process was done using four stages; first authors obtained relevant articles, arranged them in alphabetical order and ensured the readability by getting familiar with the content of the text. Secondly, researchers used coding to create the upper (main) and lower (sub) categories by pasting into Microsoft word possessor to ensure the connection between the ideas they expressed. Thirdly researchers cross checked if there were overlapping sub-categories and finally ensured that the sub-categories carried the core themes of the main categories.

6. Results

The results of this study intend to answer the question, what kind of social developmental challenges do adolescents with cancer face? Three main categories with five sub-categories were obtained from previously researched data.
6.1 Relationships

Isolation from peers and treatment-related cognitive impairments’ can hinder the development of social skills required for the initiation of relationships. (Newby et al., 2009,113). According to Larouche et al., 2006, cancer in adolescent’s causes altered social functioning e.g. disruption in education and interpersonal relationships.

6.1.1 Family Relationship

Family dynamics can be compromised when an adolescent is diagnosed with cancer because it causes changes in the role of family members. The adolescent may not be able to fulfil their usual roles and siblings may need to assume aspects of adult roles. (Robert et al., 1998,3). The changes in family dynamics can also impact on the adolescents’ siblings as they may be at a higher risk of psychosocial problems. (Robert et al., 1998,3).

According to family-system, perspective, the functioning of parents and the family influences the functioning of children and vice versa. In several studies on childhood cancer, parental distress was found to be correlated with the emotional functioning of children, but it’s different to determine the direction of the correlation. (Patenaude et al., 2005,9).

6.1.2 Peer Relationships

Across the studies of children with varying forms of cancer and treatments, recent evidence suggests that experiences with childhood cancer treatment may have implication for children’s social functioning and peer relationships. Survivors of childhood cancer have been found to engage in less than half the number of social activities as their peers. (Pendley, Dahlquish & dreyer, 1997,29). They are also rated by parents as having poorer social competence and are seen by peers as sick, fatigued, and absent from school. (Kullgreen, Morris, Morris & Krawiecki, 2003,1).
Survivors rate themselves as having fewer close and confiding relationships when compared to children to children who never had cancer. (Sloper, Larouche & Charlton, 1994, 163). They are also less likely to be seen by peers as having best friend. (Reiter-purtill, Vanatta, Gerhardt, Correll, Noll, 2003, 467), are chosen by peers less often as a best friend and receive fewer friendships nominations from classmates. (Vanatta et al., 1998, 279).

6.2 Self Development

Adolescence and young adulthood are periods of development particularly susceptible to disturbances. Adolescents and young adults make the transition from childhood into the adulthood as they develop physically, psychologically, sexually and socially. Independence from family, identity formation, focus on appearance and self-image, development of intimate relationships, adjustment to pubertal growth, as well as establishing future goals are all hallmarks of adolescence and young adulthood.

6.2.1 Confidence

Throughout their experience with cancer, adolescents experience a sense of losing their confidence because of the many challenges of having cancer especially the fact that they cannot control the situations. During adolescence a large portion of self-esteem is derived from sexual identity. Cancer, during this developmental period, may present certain challenges in establishing a positive sexual identity. Obstacles in accessing sexual health knowledge difficulties in interpersonal relationships and body image concerns may be hurdles that adolescents and young adults with cancer confront in pursuit of sexual health, which may, in turn, hamper the development of positive self-esteem. (Kyngäs et al., 2000, 6)

The adolescent with cancer has to deal with physical changes as a result of their treatment in addition to the usual developmental changes, which can lead to adolescent with cancer having trouble maintaining a positive body image. (Carr-Gregg et al., 1987, 496). The notion of self esteem refers to the level of degree to which one value or likes oneself. The ‘self’ evolves through a cognitive-
developmental maturation process. (Harters, 1983), and continues to be influenced by an individual’s direct and indirect experiences with his/her environment. (Bracken, 1996).

6.2.2 Identity formation

According to (Arnette 2000, 469), identity development is a key aspect of healthy growth and development for adolescents and young adults. Successful achievement of this milestone requires healthy peer relationships as identity develops within the context of social interaction. However, isolation and alienation are commonly reported among adolescents and young adult patients and survivors, as they often miss out on experiences that their peers are enjoying such as dating, leaving home and establishing independence, going to college, pursuing gainful employment, getting married or having children. (Zebrack, Hamilton, Wilder, 2009, 468)

To arrive at this last stage of identity achievement, adolescents need to feel emotionally independent enough from their parents so that they base their chosen ‘self’ on a decision-making process that is uniquely their own. (Marcia, 1966, 551). This is a process in which they need to reconcile the past ‘self’ of the childhood and the imagined future ‘self’ of the adulthood. They carry out this reconciliation through an interactive process with their social environment in order to achieve their present identity. (Erik Erickson, 1998)

6.2.3 Career path.

Studies have shown that young survivors could report a negative impact of cancer on their vocational aspirations lower professional expectation or less concrete plans for the future. (Servitzoglou, Papadatou, Tsiantis & Vasilatou, 2008, 29). Besides poorer academic performances due to frequent absenteeism from school during periods of illness and hospitalization, it might delay opportunities to explore personal and occupational interests. Moreover, poor health in childhood might influence educational aspirations, resulting in a projection in long term educational goals. Fear of recurrence of health conditions induced by treatment toxicities might influence survivors in their planning
about education plans, and, therefore might negatively affect their educational and occupational achievement. (Boman et al., 2004,354).

6.3 Course of life

The developmental consequences of growing up with or after childhood cancer may have consequences in adulthood. The fulfilling age-specific developmental task in childhood is of great importance to the adjustment in adult life. (Garber, 1984,30). The developmental tasks and the resulting developmental milestones that are necessary in the development of a child are referred to as the ‘course of life’. The normal developmental task of childhood and adolescence involve the attainment of social and academic competence, and the development of peer relationships and increasing independence from the parents. (Goudena, Groenendal, 1994, 59). Achievement of identity might be problematic for adolescent cancer survivors. (Madan-Swain, Brown, Foster, Vega, Byars & Rodenberg, 2000, 105).

7. Ethical Consideration

Ethics is a generic term for various ways of understanding and examining the moral life. Morality refers to ‘norms about right and wrong human conduct that are so widely shared that they form stable (although usually incomplete) social consensus’ (Beauchamp & Childress, 2013), such as not lying, stealing, or killing, keeping promises and respecting the rights of others.

The ethical principles that guide nursing researchers are the same that guide nursing practice. These principles are set out in the codes of conduct nationally or internationally. (Moule & Goodman 2009,56). Ethics is a complex issue in research as it entails particular values and beliefs that determine how a research should be approached. (Graham & Fitzgerald 2010, 134). When undergoing a qualitative research, ethical procedures should be followed due to the sensitivities of some of the topics involved. Ethics can be viewed as moral principles with ethical questions “woven
through every aspect of research, shaping the methods and the findings”. (Alderson & Morrow 2011, 5).

Since the methodology for this study was systematic literature review, the research was focused on those rules that are applicable to ascertain authenticity. Data bases were searched thoroughly to obtain articles which are screened without bias against predefined eligibility criteria. In order to ensure trustworthiness and reliability, articles were double check to ensure that they were accurate and peer reviewed. It is true that no research work can be considered ethically perfect; hence those views which were considered credible were ensure to avoid plagiarism and use the right text referencing technique to report findings.

7.1 Reliability & validity

Reliability refers to the consistency of a tool to measure what it is intended to. A nurse researcher however is interested in three measured of reliability which includes the stability of a measure, its internal consistency and equivalence. Validity refers to a measure of whether a data collection tool accurately measures what it is intended to. (Moule & Goodman 2009, 184-186). Trustworthiness aims to support the motion that the research findings were worth considering. Credibility refers to reports or publications being authentic so that the readers can believe that the data presented were a true reflection of the participants’ view, experience or belief. (Moule & Goodman 2009, 188). Credibility was ensured by following the appropriate method of conducting a systematic research. To ensure transferability, researchers researched methodology in detail so that it could be repeated. Plagiarism was avoided by using paraphrasing and referencing as recommended. Quotations marks were used sufficiently in some instances where the researchers want to retain the original meanings
of some information and references were equally provided for any citation used. Only scientific and evidence based articles were used to proliferate authenticity.

This study is dependable as authors started by describing the background of the topic. The details of data collection process were also given in a way that can be easily confirmed. This guarantees dependability. Only scientific and evidence based articles were used to proliferate authenticity. This thesis also excluded some certain themes that the authors supposed were not eligible to the inclusion criteria. These themes were excluded as a result of the fact that the research process was rigidly streamlined to a particular pattern that could not be changed because doing so would have translated to data manipulation which would have affected the legitimacy of the thesis.

7.2 Strength and Limitations

This study was able to answer the research question through the obtained articles. The analysed articles were relevant because most of them fitted in the inclusion criteria and were obtained from different parts of the world, Asia, America, Europe and Australia. This study will be relevant to the Länsi-pohjan Keskusairaalta and it will provide new information to nurses and students nurses about the challenges cancer adolescent patients face. This study faced some limitations like most of the important articles were old as there have been few researches made in identity formation and adolescent development. Fewer articles were found in this topic compared to other topics. Many articles with relevant information were not available in full text and this caused a major setback for the study.
8. Conclusion

The following social developmental challenges in adolescents with cancer were obtained from this study, Relationships (family and peer), personal development (Identity development, confidence, and career path) and course of life. Relationships were largely discussed in most of the articles that were found, because forming relationships is one of the most important aspects of life, we can say it’s the ‘essence of life’. It is from other people that we learn and this promotes personal growth and identity formation. Cancer in adolescents affects their relationships with others leading to social isolation.

Identity development is a key aspect of healthy growth and development for adolescents and young adults. Successful achievement of this milestone requires healthy peer relationships, as identity
development occurs within the context of social interaction. (Arnette, 2000, 467). Successful achievement of this milestone requires healthy peer relationships, as identity development occurs within the context of social interaction. Identity development is a very crucial part of one’s life because it makes us different from others. Being different from others, and being an individual is very important as you learn independence, can make own decision about relationships, career etc. To arrive at this last stage of identity achievement, adolescents need to feel emotionally independent enough from their parents so that they base their chosen ‘self’ on a decision-making process that is uniquely their own. (Marcia, 1966, 551). Unfortunately, cancer at this important stage of development changes the course of life and the adolescent doesn’t follow the ‘normal stages’. This leads to challenges in identity formation for the adolescent.

Loss of confidence was something that came up so strongly in all the articles, treatment of cancer leads to changes in body image and at the adolescent age where body image is very crucial. Poor body image and sexual identity, leads to loss of confidence. The cancer adolescent patient is afraid of having an intimate relationship with the opposite sex because they feel that they do not look good enough, they lack self esteem. Studies have shown that young survivors could report a negative impact of cancer on their vocational aspirations lower professional expectation or less concrete plans for the future. (Servitzoglou, Papadatou, Tsiantis & Vasilatou, 2008,29).

9. Discussion

Adolescents with cancer face a lot of social developmental challenges and as seen in this study this challenges affects their social development and identity formation. However, with social support we can help them go through this difficult journey with ease and confidence. Social support refers to the perceived availability of friends and family to help a person cope with stress. (Orerholser, 1990, 71). For children with cancer, social support also contributes to personality and social development. Social support is a multi-dimensional construct that involves the type of relationship, the type and frequency of supportive behaviours and the quality support. (Woodgate, 2006,122). In terms of coping, social support can be considered a coping resource, as social resources contribute to the (re)interpretation of the meaning of stressful situations. For example, social support can cause the situation to be perceived as less threatening. In this way, social support affects individuals’ well-
being indirectly by alleviating the consequences of stressful life events. Social support may also influence the use of other coping strategies. Positive social relations are considered to improve the quality of life of individuals in general and to protect or buffer them from stressful life events, such as cancer. (Woodgate, 2006,122).

Support groups should be created with other cancer adolescent patients and they can be allowed to do things within their age group. Through this group confidence will be boosted and identity formation will be achieved. These groups can encourage and support the issues of career path, studies, relationships with opposite sex and confidence. Nursing students and nurses can also spare few hours weekly to talk and listen (their fears and hopes) to the adolescents with cancer. This will provide support too from the health workers. The results of this study will be used at the Länsi-Pohjan District Hospital cancer polyclinic, as a guide for them to improve their understanding and care of adolescent cancer patients. The results will provide knowledge to nursing students and they will be more equipped when they go for practice placement. They’ll understand the cancer adolescent patients and in return they will give them support and good care. In the course of doing this research, the authors learnt a lot about cancer in adolescents and identity formation. The authors hope that this study can be developed in future to answer the question, how do the social developmental challenges in adolescents with cancer affect their identity formation?

10. REFERENCES


American cancer society. 2011, 2289).


Social Care Institute for Excellence. 2006. The conduct of systematic research reviews for SCIE Knowledge reviews.


Read: 25.02.2015.

Appendices

Diagram1. Influences of social development

Graph1. Common types of cancers in AYAS

Inclusion and exclusion table 1

Data collection table 2

Data Extraction Table
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<th>Author &amp; year of publication</th>
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<td>Evan Elena E., Kaufman Miriam, Cook Andrew B., Zelter Lonnie K., 2006.</td>
<td>Pubmed</td>
<td>Understanding within a development of context the identity formation stage of the adolescent and young adult can better guide health care professionals in shaping treatment choices and making decisions about how sensitive issues such as sexuality or issues relating to self esteem could be raised.</td>
<td>Scientific journal</td>
<td>Deferring to the patient as the expert of his/her own story, can be an empowering tool for young patient who is not only confronting the developmental tasks of adolescence and young adulthood, but is also making the life-altering journey through cancer treatment.</td>
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<td>Madan-swain A., Brown RT., Foster MA., Vega R, Byarst K., Rodenberg W., Bell B., 2000</td>
<td>Pubmed</td>
<td>To investigate identity formation among adolescent survivors of childhood cancer. Family functioning, perceived emotional support from family and peers, life stress and anxiety produced by the cancer experience also were examined as they influence identity development.</td>
<td>Qualitative Research (Interview)</td>
<td>A greater frequency of survivors than their healthy peers was found within the foreclosed identity status. Factors associated with foreclosed identity status included cancer diagnosis, symptoms of post traumatic stress disorder and family functioning characterized by greater levels of conflict.</td>
<td>Data were interpreted to suggest that the foreclosed identity status may serve a protective function in assisting survivors to cope with the stressor of cancer experience.</td>
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<td>Zebrack Brad J.</td>
<td>EBSCO</td>
<td>A systematic Literature Review</td>
<td>Psychosocial and behavioral interventions for adolescents and young adults cancer patients and survivors often involve assisting these individuals in retaining or returning the function in significant social roles such as spouse, parent, student, worker or friend.</td>
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<td>Wu Li-Min, Sheen Jiunn-Ming, Shu Hsiu-Lan, Chang Shuchen and Hsaiao Chih-Cheng.</td>
<td>EBSCO</td>
<td>To report a study examining the relationships among coping, anxiety and resilience and to identify predictors of anxiety and resilience in adolescents undergoing cancer treatment.</td>
<td>Cognitive coping and defensive coping are predictors for the level of anxiety and resilience in adolescents undergoing cancer treatment. Health providers should evaluate coping behavior in patients and work towards a cognitive and problem-oriented coping style that will benefit the patient’s mental health during treatment.</td>
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<td>Wu Li-Min, Chin Chi-Chun, Haase Joan E. And Chen Chung-Hey.</td>
<td>Elsevier</td>
<td>Report of a study of the coping experiences of Taiwanese adolescents with cancer.</td>
<td>Understanding adolescents coping processes relative to cancer can facilitate the establishment of a more supportive milieu. The findings can provide guidance for instrument development on coping or</td>
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<td>Lee Mei-Yin, Mu Pei-Fan, Tsay Shwu-Feng, Chou Shi-Shang, Chen Yu-Chi. 2011</td>
<td>JBI Connect</td>
<td>Qualitative study</td>
<td>To describe the body image experience of children and adolescents with cancer.</td>
<td>Children and adolescents with cancer also experience various problems associated with body image change. Repeated course of treatment lead to loss of a normal orderly life and may even result in change in interpersonal interaction.</td>
<td>The implication for practice includes: 1) Clinicians should be aware that children and adolescents with cancer feel that they are kept away from normal body.2) Clinicians should be aware that children and adolescents with cancer feel they have lost their identity.3) Clinicians should understand the protective strategies that children and adolescents with cancer develop and utilize with support from family and friends.4) There should be a strategy to facilitate the development of positive attitudes.</td>
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<td>towards the illness and body image change in children and adolescents with cancer.</td>
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