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Acknowledgments

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Abstract

The objective of this research study sets out to examine how are families affected by childhood cancer? Development within scientific research linked to treatment and care have seen survival rates increased for children diagnosed with cancer. However, childhood cancer does not just impact the child diagnosed but affects all individuals involved with the family.

Secondary analysis was carried out using pre-existing literature, selecting four studies to examine in-depth and provide a holistic insight into family life when dealing with a diagnosis. A mixed methods approach was used combining qualitative and quantitative research to give greater understanding of the impact childhood cancer had on family life by combing the strengths of the approaches.

Findings identified that families were negatively affected by childhood cancer with many parents struggling with the increased pressure to provide a normal life for themselves and their children. Research identified that parents were likely to have higher psychological distress soon after a diagnosis which related to having little social support or lower financial income. Also, there was a correlation between family functioning and children’s attachment with their primary caregivers. A limitation of the study can be linked with the number of participants used within the articles and the inexperience of the student researcher. A positive element of this review identified that families do overcome the stress and turmoil which was linked to family support.
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Chapter 1. Introduction

Paediatric cancer affects thousands of individual lives each year, however it does not just have an effect on the individual child, but also has an impact on parents, siblings, extended family and friends. The researcher wants to explore ‘How are families affected by childhood cancer?’ The study will focus specifically on childhood cancer producing an in-depth analysis exploring the journey from the initial diagnosis to treatment methods of the disease. Secondary analysis of published research will be used to synthesise knowledge of the subject considering the gaps within the research, which in turn will improve information for professionals. Enabling them to effectively ease the journey for those families who require additional support and resources. The review will analyse existing literature, exploring the themes surrounding the subject of paediatric cancer, investigating how this can change family units after a diagnosis.

Cancer, is a word which often strikes fear in many people within society. Even though survival rates have increased in recent years’ cancer is a term which correlates as a reason why people do not access health care at the earliest time (Johnston et al., 2010). This is usually due to the apprehension of the unknown which comes attached in getting professional help (Moser et al., 2014). Historically the term was perceived as a death sentence nevertheless, within contemporary society there have been huge changes and developments directed towards treatment and medical resources. Reform can also be associated with policy and government intervention involved with the specialised care of the disease (Maris, 2015). Research conducted by Ahmad et al. (2015) identified that there is nearly a 50% chance of males developing cancer throughout their lifetime aged between 0-64, whereas females have a 40% chance of developing the disease within the same age category. Nonetheless, cancer does not specifically target one type of individual within society but can affect anyone, from any gender, ethnicity and age (Herb, 2014).

Cancer is an umbrella term used for many forms of the disease, however they all share the common formation which involves the development of uncontrolled cells, which can affect
any region of the human body including organs, tissues, bones and skin (W.H.O., 2017). The diagnosis of cancer can be categorised into two stages. The first category is the stage where the cancer begins and stays confined within that area, this is also referred to as the primary cancer. The second stage, defined as the secondary cancer means the cancer has spread and travelled through the blood and the lymphatic system to other parts of the body. At this stage, the cells are reproducing at an incredibly uncontrollable rate thus causing new tumours to develop (Donellan, 1999).

Childhood cancer is vastly different to adult cancers as it affects different parts of the body compared to adult cancers and children have stronger doses and longer treatment courses. Children have a lot more energy and strength and can withstand greater intensity levels compared to adults who have caused damage to their bodies through external factors such as their environment, alcohol and tobacco (Macmillan Cancer Support, 2014). However, the cause of childhood cancer isn’t associated with one definite reason but is linked to many risk factors such as parental age, birth weight and environmental exposure to such things as radiation. Not only is childhood cancer frequently associated with D.N.A and gene mutations taking place within the body but is associated with previous treatment for cancer which can increase the likelihood of developing cancer again (Maris, 2015).

There are many different types of childhood cancers. Leukaemia (cancer of the blood) is the most commonly diagnosed cancer within children. Brain tumours are the most common form of a solid malignancy whereas Lymphoma (cancers within the lymphatic system) and Neuroblastoma (cancer of specialised nerve cell) are some of the most common forms of cancers which children develop (Dommett et al., 2012, American Cancer Society, 2016). It must be acknowledged that children can develop cancers which usually affect adults but this happens very rarely (Davidoff, 2010, Children with Cancer UK, 2017b).

Cancer within children statistically accounts for less than one percent of all cases reported. Since the 1990’s incidence rates have increased by eleven percent. A possible explanation can be associated with parents getting their children to be
diagnosed more efficiently. This linked to the referral system improving shows a correlation with 82% of all children diagnosed with cancer surviving (Cancer Research UK, 2017). Additionally, statistics within the UK illustrate less than ten percent of children die within the first year of diagnosis and only two percent of all childhood cancer cases die within the first 30 days (National Cancer Registration and Analysis Service, 2013). Nonetheless, cancer still accounts for one of the main causes of mortality within children in the UK alone. Even though there is constant development concerning health planning and primary care provision within paediatric oncology (Feltbower et al., 2004, National Cancer Registration and Analysis Service, 2015).

When a child is diagnosed with cancer the entire family network is affected these include parents, siblings and grandparents. Even extended family members and friends are affected by the entire process, particularly within contemporary society, especially in the western culture as family life is centred on diversity (Giddens and Sutton, 2013). An illness of a child can shatter relationships and affect family life tremendously which is linked to the development and growth of relationships alone (Beckett and Taylor, 2010). This study aims to explore the impact of cancer on the family system and gain an insight into how they cope through the experience of having a child develop cancer within a family. Drawing upon themes which the family go through together as a unit, whilst analysing how children and parents are affected throughout this journey.
Chapter 2. Literature Review

How does cancer treatment affect children?
From the initial diagnosis of cancer, children are subjected to many tests and procedures to achieve the correct diagnosis and be given the precise treatment. Consequently, this can be a difficult period for the children as having these tests completed can cause a lot of pain. Additionally, there are a lot of big changes which take time to adjust for the child and family involved, new routines must be created associated with having to spend time in hospital away from the family home (Children’s oncology group, 2008). Children of a younger age may not have the ability to explain the symptoms they have been experiencing, this can be associated with children’s development stages (Marcus, 2012). However, other factors must be taken into consideration when trying to understand the effects on children; focusing on different genders, cultures and more importantly cognitive development (the capability to comprehend) (Becket and Taylor, 2010). Previous research suggests that children with cancer find themselves being overpowered with their situation which affects their ability to discuss their condition as they are frightened to express their fears and emotions (Yi et al., 2016).

Cancer treatment and side effects
Children diagnosed with cancer going through treatment have to face a lot of adjustments within their lives. For some children, they face the possibility of having surgery to remove the tumours, which can be a very invasive procedure and for some children is not a solitary experience, resulting in multiple surgeries (Barr et al., 2001). Conversely, there are various complications which arise for each child going through surgery, including infection, haemorrhage and with each type of cancer presenting its own risk elements (Miller and Andressy, 2003). Furthermore, it must be acknowledged that each child can develop different reactions which results in each child having different recovery times, influencing the plans of their additional treatment methods (Lorenzo and Ramo, 2016, Sandoval et al., 2016). Furthermore, research conducted by Fox et al. (2016) agrees that some children enduring treatment experienced increased stress levels and negative emotions. However, not all children experience the same
emotions as some children stay calm and collected throughout the procedure. However, many children who have been diagnosed with cancer will have to receive chemotherapy and radiotherapy which alone cause many negative side effects. Overall, treatment will affect the children’s quality of life related to their health which has an impact on their physical, intellectual, emotional and social well-being (Momani et al., 2016).

Chemotherapy can cause different side effects for each child. It reduces the rate of cell growth and division of tumours; its main function is to stop the cells dividing and stop the indicators which start new growth of cancer cells. However, a weakness of this method is that it destructs the normal cells along with cancerous cells within the body as it cannot distinguish whether the cells are cancerous (Souhami and Tobias, 2005). Chemotherapy can result in several side effects such as hair loss, nausea and vomiting resulting in loss of appetite and weight. Conversely, there are internal side effects such as the body not producing the amount of blood cells which the body needs to fight infection and carry oxygen around the body. The reduced production of red blood cells can cause Anaemia and result in fatigue (Children with Cancer UK, 2017a, Ruland et al., 2009). Additionally, children going through chemotherapy have a higher chance of developing an infection due to the body’s white blood cells not being able to fight off an infection as they have been destroyed from the high toxic drugs used to destroy the cancer. Overall, damaging the immune system which plays a very important role within the human body, especially when an individual is diagnosed with cancer, the immune system itself can decide whether to destroy or encourage cancer growth (Pecornio, 2012).

Radiotherapy equally affects children negatively regarding their physical health and well-being whilst receiving treatment, the process involves the use of x-ray and gamma radiation solely directed towards the area of cancerous tissue (Pannall and Kotaske, 1997). The purpose of radiation is to breakdown the DNA stopping the cancerous cells from multiplying. However, a side effect from the treatment involves normal cells being damaged within the surrounding area of the cancerous tissue (MacMillan, 2014a). Consequently, the treatment can cause
irritation to the skin due to radiation burns and effects the bone marrow (Weinburg, 2014).

Steroid medicines are also used within children’s treatment plans, they can either work on their own or be provided with chemotherapy, as an attempt to remove cancer cells more effectively. Steroids used to treat cancer are referred to as corticosteroids and they provide the body with energy and reduce allergic-reactions (Cancer Research UK, 2015). However, steroids used within paediatric oncology do not come without the risk of side effects which include glucose intolerance, gastritis and myositis (inflammation of muscles) (Belgaumi et al., 2003). In addition, side effects of steroids include increased weight gain, appetite and can cause moods to fluctuate resulting in an increased level of irritability. Nonetheless, steroids are used in cancer treatment to reduce swelling caused through treatment methods, in addition to relieve nausea and vomiting especially as children are given higher treatment intensity levels (Macmillan, 2014b, Woodgate et al., 2003). Steroids frequently have a serious impact on the individual child, they can develop increased levels of anger and outburst of violent behaviour linked to their mood swings (Mrakotsky, 2011).

Pain
Cline et al. (2006) signifies the experience of pain for children diagnosed with paediatric cancer as a current issue which has a great impact on children and their families during active treatment. Highlighting that many children indicate the pain imposed from treatment as more painful than the cancer itself (Oberfield, 2007). Nilson et al. (2009) emphasises treatment trajectory for children as a grief period which can create anxiety and fear with medical practices within the future. Thus, creating emotional and psychological distress for the child diagnosed with cancer however, the pain experienced does not just impact the child diagnosed with cancer but also creates negative outcomes for the parents (Last and Grootenhus, 1998). However, Young (2005) highlights that pain is a subjective response and identifies factors such as a child’s development stage, environment and interaction with parents along with medical staff influence the pain experienced for each child. Kuppenheimer and Brown (2002) distinguish some of the symptoms and side effects experienced by children, highlighting that the disease itself can generate pain associated with tumour attachment to soft
tissue and bone. Children will go through multiple procedures such as bone marrow aspirations, lumbar punctures and the high probability of having an implantable port inserted (Matziou et al., 2016). Spagrud et al. (2008) highlighted that many children find it difficult with the numerous number of needles they are subjected too and develop a fear of needles, resulting in some children having to be restrained. Medical professionals can insert an implantable port for children going through short or long-term treatment processes. The implantable port is inserted to provide medical staff a much simpler route to insert needles (Esfahani et al., 2016), producing less trauma for the child when collecting blood samples, giving blood transfusions and delivering treatment such as chemotherapy (Ugur et al., 2014). However, children can experience pain through this procedure which is delivered through general anaesthetic. The procedure may cause children to feel uncomfortable where the port is inserted plus the additional side effects from the anaesthetic and possibility of an infection (National Cancer Institute, 2015).

Lumber punctures involves a needle being inserted into the hipbone or spined column to remove the fluid for investigation. The procedure requires the patient to rest for many hours after the practice which can be difficult for children to stay stationary to eliminate the possible side effects (Matziou et al., 2016). Bone marrow aspiration biopsies involves medical professionals extracting a sample of bone marrow from the patient’s hip bone in the lower back to be assessed and examined (Bain, 2001). Van Cleve et al. (1996) highlighted that age plays a significance in children and their pain response associated with lumbar punctures and bone marrow aspirations. Findings identify that younger children are far more expressive of their pain compared to older children going through the same treatment. Overall, the effects of pain can create complex issues for children going through treatment, pain is not a solo symptom but is joined by fatigue and distress reducing the child’s quality of life. Children’s behaviour is undoubtedly transformed when experiencing pain as they may develop resistance through crying and screaming to avoid the treatment procedures. Subsequently older children may feel humiliated because of the behaviour they displayed whilst some children become withdrawn and outraged with medical professionals and their parents (Bryant, 2003, Nilson et al. 2009).
Psychological impact on the child

Generally, a diagnosis of cancer within a child can have a negative impact on their mental wellbeing. Increased levels of stress have been identified with a diagnosis and linked to the stages of active treatment (Marcus, 2012). Psychologically children have to face transformations to their bodies through the result of the treatment as a result this affects their body image which has an impact on their self-esteem (Fan and Eiser, 2009). Additionally, whilst going through treatment children have increased sleep disturbance stages which can be connected to their behavioural changes. Children experiencing sleep difficulties can commence from the diagnosis and continue throughout active treatment and even remission (Orkin et al., 2009, Eiser, 1998). Additionally, paediatric oncology patients have increased level of EDS (excessive daytime sleepiness) which negatively impacts their quality of life. Fatigue and lack of sleep can be associated with children developing increased levels of risk taking, lack of concentration and learning difficulties (Kayeyias et al., 2012, Walter, 2015). Furthermore, it must be acknowledged that each child’s treatment process is unique and suited to their needs which can result in different psychological issues for each child. Moreover, research suggests that many children diagnosed with cancer do not recognise themselves as being “poorly” prior to commencing treatment but associate being sick with the side effects from treatment (Woodgate et al., 2003). Psychologically children diagnosed with cancer have increased levels of anxiety and depression which correlate with having a higher percentage of being emotionally distressed (Zelter et al., 2009). Additionally, research identifies children diagnosed with cancer responding to distress through vast alterations to their personality and temperament to cope with the circumstances (Harper et al., 2014).

Depression and anxiety are the two most common psychological side effects which children develop whilst going through treatment (McCaffery, 2006). Depression is a common negative indication which many children feel after being diagnosed with the disease. Usually the course and length of treatment affects the child’s everyday life and consequently the child has a higher percentage of developing negative thoughts and feelings (Eiser et al., 2005, Herrmann, 2015, Mind, 2013). Anxiety is also another common psychological impact for children
diagnosed with cancer. Anxiety can have a negative effect on the development and growth of the child with cancer, especially as this can stop the child wanting to socialise with friends or siblings after having treatment. As a result, the child diagnosed no longer has the desire to take part in activities which previously interested them resulting in further psychological stress (Fan and Eiser, 2009, Young Minds, 2017).

The meaning of cancer to children also has a marked impact on their psychological behaviour (Herrmann, 2015). Whilst children of an older age have the ability to think logically about their illness, it must be acknowledged that younger children may not understand the significance of the disease (Armstrong and Reaman, 2005). The increased amount of time participating in treatment can result in individuals questioning and becoming more apprehensive over their own deaths (Moody et al., 2006). This intensifies especially when friendships are made with other children with cancer who have not responded to treatment and have deceased. Consequently, those children who are much younger relate the disease with naughtiness and not behaving accordingly to what is expected of them (Hymovich, 1995). Koopman et al. (2004) identified this understanding with children and what they have been educated concerning illness and disease but also included their level of cognitive development. Furthermore, younger children have not developed the skills to be able to distinguish the mind and body in relation to illness and disease and what causes people to become ill (Hymovich, 1995). In conclusion, the misinterpretation regarding the meaning and understanding of cancer to children could easily be dissipated through parents and professionals opening the lines of communication and developing resources (Knighting et al., 2011). Produced appropriately for the child’s cognitive and social development stages, this can reduce the fear and obstacles which stop children sharing their concerns and worries with parents and health professionals (Gibson et al., 2010).

**How childhood cancer affects parents**

Research has shown that parents who are dealing with a child diagnosed with cancer have an increased likelihood of developing psychological distress. Consequently, they can develop depression, anxiety and insomnia many parents
develop post-traumatic stress disorder (Ljungman et al., 2014, Jones, 2012). The journey parents face is often challenging and tests their ability to cope, whilst dealing with the ill child and still manage the parenting of healthy children. Parents described the overwhelming sense of guilt after a child had been diagnosed with cancer (Popp et al., 2014). Evidence within previous research indicated that it played a big emphasis on how parents coped with the reality that their child had a life-threatening illness (Evans et al., 2015, Bradford, 1997).

**Resilience and Stress**

Resilience can be defined as the ability to endure challenging situations within life and the aptitude to overcome the troubles which individuals are faced with (Lishman et al., 2014) A study conducted by Gudmundsdóttier et al. (2011) studied parental reactions when a child was diagnosed with cancer, focusing on the resilience which families develop. Data from the review highlighted that parents who were organised were more likely to be rational whilst managing their situation coping with the increased levels of stress. By contrast, those parents who identified with little or no organisation identified with greater risk of being unable to become resilient. Additionally, research conducted by Bemis et al. (2015) identified that stress was a difficult element most parents found problematic to manage when trying to remain resilient. Many parents struggled with providing both emotional and physical support to their ill child and healthy children, they found the dual role difficult resulting in their resilience diminishing (Speechley and Noh, 1992). Research conducted by Norberg et al. (2005) emphasised that stress within parents was measured at a much higher rate with mothers compared to fathers. Even though within society many parents have combined roles involving parenting their children. Research suggests that mothers spend more time with the child diagnosed with cancer, experiencing the distress compared to the fathers going through the situation (Miedema et al., 2008, Fleming et al., 2015).
Quality of Life

Quality of life can be defined as the satisfaction which an individual acquires within their life, it comprises of a multidimensional approach which considers individual beliefs, values and culture (Momani et al., 2016). Overall quality of life centres on the individual’s well-being and how this affects their physical, intellectual, emotional and social development, which can bring both positive and negative levels of fulfilment (Poradzisz and Florczak, 2013). Quality of life becomes an important element for parents especially when they consider their children’s own quality of life. Also, treatment intensity affects the way which families take risks, overall affecting quality of life (Rodriguez and King, 2009).

Cousino and Haxen (2013) reported that parents become extremely overprotective of children (including both the ill child and healthy children) within the family which is often associated with parental stress levels. Likewise, both parents faced amplified levels of stress linked with having to deal with the possibility that their child might not recover from cancer. Controversially, research conducted by Parsons et al. (2012) investigated the concept of quality of life within the family whilst children were going through active treatment. Identifying that parents often reported a lower quality of life than what their children reported. Evidence suggest that the motive behind this was linked to parents having lower levels of optimism than their children, as they understood the full impact of the illness (Van Dongen-Melman et al. 1998). Parents’ quality of life dwindles when their child is diagnosed with cancer and they find the concept of pain which their child is experiencing a very trying stage. Also, the relentless emotional support providing a fabricated optimism within the family for both sick and healthy children can result in long-term exhaustion developing and a poorer quality of life for parents (Hedén at al., 2013, Pöder et al., 2010). Research suggest that parents often feel they have failed at being a parent as they couldn’t protect their child/family from the negative impact of cancer (Kasak, 2005) Likewise, many families/ parents develop cancer related stress and post-traumatic stress disorder which highlight that guidance and support would be beneficial regarding mental health when coping with childhood cancer (Miedema et al., 2010).
Changing of roles for parents
Previous research highlights the formidable adjustments families go through, especially when the attention is on the parents dealing with their child who is diagnosed with cancer (Feyh et al., 2012, Fletcher, 2010, Long and Marsland, 2011). As previously discussed in another section mothers are generally the parent who stay with the sick child in hospital and witness the negative side effects of treatment (Miedema et al., 2008, Fleming et al., 2015). Furthermore, there is evidence which indicates that gender plays an integral part in how parents cope throughout their cancer journey (Quin, 2005). Nonetheless, Long and Marsland, (2011) identified that even though fathers held fewer responsibilities involved with caring for the sick child they were not made redundant. Throughout the journey, they had to alter their parental role and become the primary care giver for the other (healthy) siblings within the family, whilst still dealing with work and other responsibilities. Parenting roles change whilst their child is going through treatment for cancer, consequently parents’ work commitments alter and the household income is negatively affected (Gage-Bouchard et al., 2013). Research conducted by Bona et al. (2014) identified that 94% of families’ dealing with childhood cancer struggle financially and their household income is reduced drastically. This can be correlated with one of the parents having to leave or change their employment schedules to cope with the demands of keeping up with hospital appointments and caring for their sick and healthy children (Warner et al., 2014). A previous study highlights that mothers are more likely to leave employment than compared to father’s. Although fathers are more committed in providing for the family financially whereas mothers provide care and support the rest of the family (Syse et al., 2011). Isolation and loneliness also takes emphasis in what parent’s experience, whilst dealing with childhood cancer. Schweitzer et al. (2012) identified that parents reported that their marriage become a secondary concern which resulted in conflict within the marital relationship in comparison to the lives before a diagnosis. At the same time, they had difficulty adjusting to the new changes and the new life created for them, which was constructed on solely concentrating on their health of their child. Even though many parents identified lack of knowledge as to how they were in the situation they altered the role of parenting and the responsibilities that come attached to being a parent. Several couples reported that the diagnosis of cancer
had a huge impact on their marriage which was linked to less time spent as a couple. Parents dedicated more time to their child and the increased time apart created a split in parenting choices. Consequently, some parents become more lenient to the sick child’s behaviour but in comparison do not indulge the behaviour and upbringing of healthy siblings (Dahlquist, 1993, da Silva et al., 2010). In modern contemporary society, family life is no longer based on two conjugal heterosexual parents but covers all different characteristics such as step-parents, same sex couples and single parent families (Giddens and Sutton, 2013). Previous research conducted by Kelly and Ganong (2011) highlighted that decision making for children involved in families is no longer based solely on the biological parents but often includes step-parent’s views which can result in the decision-making process becoming increasingly problematic. Nevertheless, the evidence acknowledges that step-parents play a pivotal role through the provision of emotional and physical support to partners and other children involved (Russell et al., 2016).

**How childhood cancer affects Siblings**
Cancer has an impact on the entire family, siblings are just as much affected by the diagnosis and treatment process as the child diagnosed with the illness. Slomski (2012) highlighted the evidence reported by siblings who described the diagnosis of cancer as bringing the family together as a unit. Improving the bond and strength of relationships throughout the duration of the illness. Conversely, not all siblings have agreed to this statement and in some cases siblings have reported that the diagnosis created a negative influence on the family structure resulting in relationships deteriorating (Murray, 2000). This highlights that social support is required for siblings dealing with a diagnosis of cancer producing immense changes to family life (Wilkins and Woodgate, 2006). Additionally, siblings reported negative outcomes within the family unit as they experienced a sense of detachment from their parents and resulted in them having to spend more time with other family members. Evidence suggest that siblings affected by cancer keep emotions to themselves and process information they don’t understand (Ballard, 2004, Children’s Oncology group, 2008). In addition, there is evidence which indicates that the role of sibling’s transforms throughout the journey. Particularly when associated with older siblings who can develop an
increased level of maturity and become more responsible for their actions when a sibling is diagnosed with cancer (Sargent et al., 1995).

Research focusing on siblings dealing with childhood cancer reported siblings developing emotions with increased levels of jealousy and anger, as parental time with the ‘healthy’ children decreases due to more time being spent with the ill child (Hymovich, 1995, van den Hoed-Heerschop, 2007). However, healthy siblings also reported feelings of fear and guilt whilst dealing with the diagnosis, which is associated with siblings becoming more aware of their own health and death. As a result, depression and anxiety symptoms increase as they struggle with the new changes within their lives (Houtzager, et al., 2003). Furthermore, healthy siblings are at increased risk of developing emotional deprivation which impact their well-being and growth. Likewise affecting the choices, they make, not just at the time of diagnosis and treatment but throughout all stages of their lives (Knecht et al., 2015).

When considering anxiety and depression (emotional effects) within healthy siblings the age of the child must be taken into consideration. Nolbris et al. (2010) suggests that younger children lack understanding of the disease which is correlated with findings, that children do not understand the illness that affected their siblings. This can be associated with individuals being unable to express their thoughts and feelings which increased the negative effect on their quality of life (Knecht et al., 2005). In addition, Houtzager et al. (2004) reported that healthy children go through lengthy periods of isolation and separation which can be linked to the treatment of the ill sibling. Parents and other family members often focus their time and attention on the ill child. Consequently, this causes negative behaviour to occur and can result in children creating conflict to gain attention and develop a sense of rivalry with siblings (Lane and Mason, 2014). Overall, children who receive less social support from their parents and family members are not able to cope with the demands of childhood cancer (Knecht, 2015, Murray, 2000).

Childhood cancer can impose a negative impact on children’s school attainment. French et al. (2013) identified that children diagnosed with cancer and their
siblings have a lower school attendance. Correspondingly healthy siblings low school attendance resulted in them developing negative behavioural patterns and emotions. Additionally, O’Shea et al. (2012) established that negative behavioural patterns were based on the foundations that healthy children were separated for increased time periods away from both parents and lack of communication from not being informed of the sibling’s diagnosis. Consequently, this aided to the fears and behavioural problems of healthy siblings, causing mood swings, withdrawal and frustration (Ballard, 2004). Conclusively, Barrera et al. (2005) highlighted that children missing school were less likely to develop social skills resulting in them becoming isolated and reported increased difficulties making and maintaining relationships. Thus, resulted in children having low self-esteem, poor quality of life and lower academic attainment.

Summary
It’s clear that childhood cancer dramatically affects a family’s life and the amount of support needed cannot be solely provided through family and friends. Support from professionals needs to be implemented for those families who are dealing with paediatric oncology. In addition, the support provided needs to be offered to all family members and include activities which bring the family together as a unit either within the home or hospital setting. There are gaps within the knowledge to discover what families need at the time and how they can be implemented to ease the pain and transition of coping as a family and not separate existences. Whilst exploring pre-existing data it’s clear that family income is a major concern but there is little evidence to explore how it affected their ability to cope and how it affected the parent’s determination to continue as a family unit.
Chapter 3. Research Methodology

This review is going to consider “How are families affected by childhood cancer?” It will focus on the impact of childhood cancer concentrating on the family, exploring how parents and children are affected as a family unit. Due to survival rates increasing families now have to consider altering the perceptions and expectations of life they once had, and consider the big changes to their family unit and individual lives. Initially the ethics form for this project set out to investigate “How is parenting affected when a child is being treated for cancer?” However, when researching and exploring the literature it become evident that there was insufficient data and literature to examine, therefore the title had to be adapted. Through background reading and exploring the literature it became evident that there was a gap in the literature focusing on the family together as unit. There was a lot of data which specifically focused on the parent’s view or just focusing on the mother’s perspective of coping with the diagnosis. There was limited amount of data which included the perspective of parents, siblings and the child with the condition. As a result, a new question was formed considering the ramifications of family life focusing on a holistic approach.

Decision to do desktop study
The research will be using secondary analysis of published work within a desktop design to synthesise the knowledge of the subject. Secondary analysis is the approach intended to be used combining quantitative and qualitative research to provide a holistic and comprehensive understanding of knowledge. The decision to use secondary data defined by Hakim (cited in David and Sutton, 2011) is based on the exploration of another researcher’s work, creating new interpretations and congregating recommendations to improve the knowledge of the subject.

Primary research was not permitted, as it is not only a difficult issue to address but also addresses difficult ethical implications, associated with direct research linked with children (Irwin, 2013). Furthermore, through using a risk-benefit assessment it was clear that the research being developed would not be socially
useful and would not benefit anyone but the researcher (Irwin, 2013, Sieber and Tolich, 2013). Additionally, primary research was avoided as secondary data facilitates the abilities of all researchers, especially those individuals who have less experience. They can avoid the barriers which primary research would present when focusing on research with children (Long-Sutehall et al., 2010). However, the approach is not only beneficial within quantitative or qualitative research but can provide good quality data through combing the approaches. Nonetheless, the researcher must acknowledge the limitations which comes attached to the method, linked to the methodology and interpretation of information (Punch, 2014). Johnston (2014) states that limitations attached to the method is directly linked to the researcher not being involved with the primary research collection and not knowing how the information was selected and viewed as important. Additionally, the secondary researcher cannot fully comprehend how the primary research was organised and how the choice of data collection and sampling affected the findings (Moule and Hek, 2011).

**Secondary Analysis**

Secondary analysis has been selected as the research method throughout this review because it supplies researchers with a wide variety of methods, accessible to all types of researchers from the inexperienced to accredited professionals (Bryman, 2012). Bowling (2009), defines secondary analysis as the starting point for all research, searching and examining data which already pre-exists which can answer the question, before considering primary research. Additionally, a further definition of secondary analysis is given by Campbell (2007) who describes it as the process of utilising collected data, which is a convenient method to gather research. This review will draw the literature together to explore the gaps within the research which need to be developed. The researcher within this literature review will be using a research driven approach, placing emphasis on the question and then exploring the pre-existing data which is appropriate to answer the question (Cheng and Phillips, 2014). Additionally, secondary analysis is cost effective but also allows time to conduct good research within a small-time scale, allowing flexibility. Studies using this method can validate their work by comparing their results produced within the first study (Coyer and Gallo, 2014). Also, the researcher will have access to high-quality data, which has been peer-
reviewed by research professionals and only quality papers will be selected. Also for a student researcher they will have access to large sets of data, which they can analyse and interpret without having to collect any new data (Bryman, 2012).

Ethics
Before conducting any type of research, an ethics application needs to be granted via the researcher’s institution. In this review, the researcher complied with completing an application for ethics approval via Cardiff Metropolitans school of Health Sciences’ ethics committee. Denscombe (2002) states that consideration of ethics is vital when conducting social research, to protect both researcher and participants. There are ethical consequences which need to be addressed at all stages through the research process, especially as researchers have a duty of care to protect participants and only conduct research for its beneficence (Norkett, 2013, Sieber and Tolich, 2013). Researchers need to implement a provision of dignity, respect and ensure the safeguarding of participant’s autonomy and ensure there is no non-maleficence throughout and after the research has been completed (Schutt, 2012).

Nonetheless, the researcher does acknowledge that even though they are conducting secondary research there are still ethical principles which need to be considered. Especially as the participants involved are part of a vulnerable group within society and much consideration has been given to factors such as informed consent, confidentiality and anonymity (Moule and Hek, 2011). However, researchers are faced with possible restrictions concerning the ethics and practicality of the processes such as gaining informed consent (Sieber and Tolich, 2013), especially within paediatric oncology as researchers must gain parental consent even though an older child may agree with participating. Their consent is not sufficient to meet ethical considerations and researchers have a duty to promote care and consideration within their work (Dupont et al., 2016). Furthermore, there were ethical issues faced when reinterpreting other researches data for example one article was selected for further analysis however was soon dismissed as there was a concern regarding the original researcher gaining informed consent and how they targeted their sample (Yardley et al., 2014).
Mixed Methods Approach

The research is going to use quantitative and qualitative data combing through a mixed methods approach. Tashakkori and Creswell (2007 cited in Ostulund et al,2011:370) defines mixed methods research as “research in which the investigator collects and analyses data, integrates the findings and draws inferences using both qualitative and quantitative approaches”. This type of research has become very significant within modern day contemporary society, especially when linked to health and social care. Through the development of health and social care services for the population within society, research has become a central element for development and without investigation advancements cannot be attained (Andrew and Halcomb,2009). Through the researcher using a mixed methods approach it has allowed for literature to be used drawing upon both qualitative and quantitative data. Consequently, the approach highlights the strengths of the two methods by combining them together to unearth the impact of the data, ensuring the widespread understanding of data and results. Additionally, the use of this approach allows the results to be generalised, especially when the topic is a complex health and social care issue (Wisdom, et al.,2012). Punch (2014) argues that the rationale for using a mixed method approach is solely for the researcher to gather more data to analyse whilst still acknowledging the weaknesses in each method. The approach allows the researcher to be sensitive through using a qualitative approach especially with the topic of childhood cancer whilst considering the variables (quantitative) in addition to the structure of families and the relationships within its system.

Qualitative data

Qualitative data takes emphasis on exploring data through the perception of those who have knowledge and understanding of the issue being investigated. One of the benefits of the approach is that it draws on distinctive concepts (Flick, 2007). Clearly et al. (2014) highlights the main advantage of qualitative research is that a topic can be explored in detail, even though sample size may be smaller than quantitative data they are chosen for a reason. Additionally, the research is undertaken within the participant’s natural setting, permitting the individual to be calm and collective when interacting with researchers (Marshall and Rossman, 2006). An additional advantage of this approach is that researchers adopting this
approach focus more on a humanistic concept, concentrating on individuals themselves using non-numerical data which is not planned. They focus on methods which gather extensive amounts of data at the beginning but then become more focused, splitting the data into categories and themes as the study progresses (Bell and Waters, 2014). Equally qualitative research has increasingly become diverse with a mix of concepts being taken into account. Especially the different variable factors which can affect the data, such as different social and economic environments (Punch, 2014).

Through this review, analysis is going to be addressed using interpretivism, allowing the researcher to use a reflective approach to understand the information within the articles. At the same time the researcher will remain critical of the data collected which addresses understanding of social activity (Howcroft and Trauth, 2005). Through the use of this approach the creation of topics and themes will emerge, and when new concepts surface it will only add to the strength of the interpretation (Marshall and Rossman, 2006). Interpretivism can be identified as the method which places emphasis on society and individuals participating within research. This method will benefit the researcher as individual subjective accounts will be taken into consideration, but also their behaviours will be interpreted. Both these elements regarded are important as they provide the researcher with information and knowledge allowing analysis (Seale, 1998). Equally the researcher will also take constructionism into account, especially as constructionism focuses on the reality of the situation within society which are continually studied and re-examined (Bryman, 2012 Silverman, 2013, Punch, 2014,). Overall, this places emphasis on data which is socially constructed, focusing on childhood cancer and directing research towards the structures of families and medicine. Furthermore, the use of constructionism, which can be classified as being a part of the ontological approach, acknowledges qualitative data within this topic which needs to be constantly produced and evaluated. To enable professionals to provide the best possible treatment but also develop ethical maturity which comes attached to the profession and research (David and Sutton, 2011, Bryman, 2012).
Quantitative data

Quantitative research takes focus on statistics with emphasis on the use of facts, exploring the relationship of the research in a systematic process. The approach provides researchers the position to conduct research without the intrusion of subjective opinions (Moule and Hek, 2011, Bell and Water, 2014). In health research, quantitative data is an essential approach to enable health professionals and researchers to explore the effectiveness of treatments and ensure reliability. Quantitative research places emphasis on using a positivist approach (Ingham-Broomfield, 2014), however Babones (2016) argues that interpretivism is much more beneficial within health research regarding quantitative data. Interpretivism is the philosophy which disputes research is focused on data within the social domain and is generated on social reality. The focus is directly on the experiences of participants, because researchers want to understand participants own beliefs and perceptions (Schutt, 2012).

Nevertheless, even though much of quantitative data is produced using a positivist approach, interpretivism can be used to understand what is actual taking place within the ‘real world’. Interpretivism acknowledges that numerical data is a method which can only add to the research. Furthermore, it can also be used to allow values and certain aspects of behaviours to be examined within society and be taken into account (Punch, 2014). Nonetheless, it does not undermine the importance of research relying on the reliability of data. This is the sole purpose whether a treatment is trialled and implemented within health care thus influencing practices and techniques adjustments (Hoare and Hoe, 2013).

Willig (2008) argues that quantitative data is based on epistemology and therefore be governed through positivism, placing emphasis on research that can be produced objectively within reality. Overall, maintaining the ideology that there should be no subjective input within research, arguing the notion that research should only have one main goal, which is to produce objective data. Data generated should be empirical and provide statistics that ensure reliability and validity which can be replicable and trusted (Schutt, 2012). Generally quantitative research is linked with positivism, asserting that objective data can be collected within social research (Punch, 2014).
Procedure

The literature included has been gained through an electronic search using Cardiff Metropolitans online data base system known as 'Met Search'. Additionally, when selecting articles, the researcher only focused on children with cancer or families dealing with a diagnosis of childhood cancer. Similarly, when researching the literature terms such as ‘paediatric oncology’, ‘childhood cancer’ ‘siblings dealing with childhood cancer’, were used to explore the pre-existing data. Moreover, when selecting articles in 'Met Search’ recommend articles were suggested through the process of a snowball effect as they were within the topic of paediatric oncology and printed in the same journal (Schutt, 2012). The increased accessibility of research data bases through online systems have resulted in thousands of published articles being available online. To narrow down the number of articles from researching ‘Childhood Cancer,’ which found 155,530 hits, through applying filters such as peer review journal, articles based on English language and from 2012 to the search down to 22,199 hits. To narrow down the number articles available the researcher only selected articles which weren’t focusing on one specific type of cancer but included a range of different cancers to improve the generalisability (Moule and Hek, 2011). Further filters were applied such as focusing on children, siblings and parents and considering how cancer affected them separately. Similarly, when selecting articles only children from zero years to eighteen were considered, even though a lot of research available included adolescents and young adult cancers. However, they were not considered as those cancers are different compared to childhood cancers including the treatment. Articles examined were chosen from 2012 onwards as treatments and technology are updated continuously within this area of health and social care. Articles included used English language however, were not specifically conducted within the United Kingdom. Additionally, when selecting articles only peer reviewed articles were chosen which upholds the standards of good quality research, which is authenticated by professionals who ensure the data is reliable and precise within that specific framework (Hames, 2007). Nonetheless, a limitation for researchers is distinguishing which research and data should be selected to use within their own research design. Consequently, the researcher within this review adopted the Critical appraisal skill programme (C.A.S.P) which is a tool which allows the researcher to select or eliminate articles
within the first two questions. Additionally, C.A.S.P also helps identify research papers limitations and strengths but is practical for professionals and student researchers (Singh, 2013).

**Summary**

In conclusion, this chapter has illustrated how data was collected but more specifically highlighted how the large amount of research focusing on paediatric oncology were condensed and what decisions were made linked to the procedure. It identified the ethical considerations and identified what ethical issues were faced whilst analysing pre-existing data. Furthermore, four articles have been selected and drawn together to gain an accurate understanding which will be examined in the following chapter.
Chapter 4. Findings and Discussion

Findings

This chapter will include the analysis of secondary data chosen to answer the research question ‘How are families affected by childhood cancer?’ Childhood cancer affects thousands of lives each year, however it is important for researchers and professionals to identify specific areas where families struggle and how they can help families overcome the difficulties faced at the time. Four studies, have been selected on a range of issues which have been highlighted within the subject of childhood cancer to try and provide a detailed account to how families are affected throughout their journey of childhood cancer. These studies will be examined in-depth providing a brief overview of the data they have produced. The study will explore the common themes identified within the different aspects of the data presented. The themes will be linked with relevant theories and supported with other research which will follow on after the findings.

A study conducted by Kästel and Enskär (2013) used a qualitative design approach using interviews to investigate the opinion of families and their involvement in providing the care of the child diagnosed with cancer. The interviews were conducted within a paediatric oncology ward which used open-ended interviews exploring the experiences of parents and their families at different stages through the first year after diagnosis. The interviews conducted used an informal approach, focusing on the narratives of participants, in total the sample were interviewed five times. Even though the sample size was small with having only eight families involved, a strength of this study can be linked with it being representative of the range of demographics included (Moule and Hek, 2011). In addition, the study did not specifically focus on one type of childhood cancer but included a range of forms of cancer to improve the generalisability of the data produced (Punch, 2014). The study obtained ethical approval ensuring the basic ethical principles were advocated such as the individual’s autonomy. The study informed participants that it was their choice to
participate and they could be removed from the study at any given time (Sieber and Tolich, 2013).

The findings conveyed that parents frequently worried about their involvement of providing care for their children, specifically as parents reported struggling with their role during their ill child’s treatment in hospital. Parents reported they felt out of control with specific reference to the medical treatment and lacked understanding of the medical jargon, yet many gained comfort from the medical professional’s knowledge and guidance. Families reported communication as a key concern especially for parents as they felt that if they did not understand the situation themselves they couldn’t openly communicate with their children. Highlighting that each family’s experience of childhood cancer varied however, there were two features which were experienced by all the families involved which was the level of fatigue and the pressure experienced by parents to adjust. However, the study does indicate that fatigue would only surface when the child’s treatment was coming to an end and their health had become stabilised (Kästel and Enskär, 2013).

Phipps et al. (2015) considered the impact of childhood cancer on parents and how they adjusted to the effects the disease had on the family psychologically. The method used involved diagnostic interviews with 305 parents of children with cancer and a comparison group with 231 parents with healthy children. The parents within the cancer group were recruited during the child’s routine outpatient appointment and the comparison group were made accessible through the school system. Researchers gained permission from the school principals who were identified as the gatekeeper to gain access to the sample (Moule and Hek, 2011). A positive element of this study is that it identified participants within both groups with similar demographics (Punch, 2014). Additionally, the analysis of the data regarding the sample were made representative of the population regarding the patients accessing the service at the hospital setting (Bryman, 2012). Informed consent was acquired from parents involved and they had to complete a sequence of questionnaires. The questionnaires provided data regarding measures of posttraumatic stress symptoms (PTSS) and psychological growth (PG) in addition to measures of global psychological functioning.
The findings within Phipps et al. (2015) identified that over 70% of parents involved reported their child's diagnosis of cancer as being the most distressing experience within their lives. However, the psychological distress experienced was measured at a much higher rate with parents whose child had recently been diagnosed with cancer. However, the evidence suggests that that even though parents struggled they adjusted through developing a resilient outlook. Findings can be linked with Bonnano’s (2012) study on resilience criteria and how parents adjust to long periods of stress. Nevertheless, the results suggested some participants developed post-traumatic stress disorder (PTSD) and the child’s cancer diagnosis was the trigger. Overall, parents whose child had been recently diagnosed with cancer reported much higher levels of PTSD than compared to parent’s children who were in remission.

Long et al. (2013) identified that treatment for cancer within childhood does not just impact the child diagnosed but also negatively affects siblings and other family members. Which had a direct link to them individually developing an increased level of psychological distress but also had a direct impact on the family’s ability to function. Participants had to fill out measures which were linked to sibling distress, family functioning as a system, parenting and post-traumatic stress. In total, there were 209 siblings aged 8-18, 186 mothers and 70 fathers who chose to be involved with the study and provided their informed consent (Moule and Hek, 2011). There were two studies conducted within this research article, study one included criteria of siblings aged eight to eighteen years and with one parent, whilst study two had criteria which included children aged eight to fifteen years and included two parents. A positive element of this study is that it included siblings, mothers and fathers within the study to gain a deeper insight to how families are affected by cancer. However, a weakness can be associated with the variable of ages linked to the sibling sample, within the two groups there was not a vast difference in age (Bryman, 2012, Schutt, 2012).

Findings within the study produced by Long et al. (2013) suggested that parents with a lower family income were more than likely to have children with higher stress levels. Furthermore, the findings identified that siblings developed high
stress levels if their parents were unable to cope with the diagnosis of their child having cancer. Siblings themselves identified more problems after a diagnosis especially the impact it had on the attachment with their parents. Families did report a lower level of family functioning after a diagnosis of cancer with many individuals developing PTSD as a result. In addition, several siblings highlighted that they had a less autonomy because of their mother’s psychological well-being.

Creswell et al. (2014) investigated the impact of childhood cancer on families’ income and how this can create psychological distress within parents. The study used multiple logistic regression analysis to examine the issues which influenced parents developing depression. 355 participants were used within the study, 215 parents had a child diagnosed with cancer, and there was a control group of 140 parents with healthy children. Informed consent was provided by all participating members of the study, a positive aspect of this study can be associated with the different socio-demographic variables to make the results more representative (Moule and Hek, 2011, Schutt, 2012). Nonetheless, the study does identify that the sample selected was a convenience sample so the results may not be generalised to all parents affected by childhood cancer (Bryman, 2012). Participants filled in surveys regarding their depressive symptoms, negative financial life events and income including measures made against the social support parents received.

Findings within Creswell et al. (2014) identified that participants who had children with cancer were more likely to develop a decreased mental health status. The findings correlated this with parents developing increased levels of concern and stress about their finances. However, those participants who reported they had depressive symptoms identified with having a low level of social support with very little help from family, friends and their community. Additionally, the findings indicated that the length of the treatment had an impact on parent’s psychological health with many identifying with psychological distress which can negatively impact the family and their role as a caregiver. The results did indicate that for those parents with higher level of support had a lower percentage of psychological distress.
Throughout the four articles reviewed there have been several themes which have been presented throughout the data, the key themes identified by the researcher will be explored within the discussion of this review. The specific themes which have been identified include family functioning, resilience, caregiver psychological impact and parental perspectives.

**Discussion**

**Family Functioning**
Childhood cancer shapes and creates many challenges for family life, undoubtedly it has an impact on the function of all family members. Families must adapt to the changes together but also on an individual basis (Banner, 1996). The child diagnosed with cancer, siblings and their parents are expected to adjust and cope with the alterations to their lives. However, parents are required to manage the care and responsibility of having a child with cancer but also incorporate the needs of other family members and themselves (Knafl et al., 2013). The concept of family functioning can be associated with family systems theory recognised by Minuchin (1979 cited in Lishman et al., 2014) which identifies the family system being made up of different mechanisms and the distinctive personalities which create a family. Heath (1996) states that system theory does not categorise family functioning with a single individual but high level functioning is based on multiple relations focusing on the strength of those interactions within a family. Walker (2012) outlines family functioning as an organic system, which alters and develops on a continual basis through the contribution of each family member not only internally but also on an external level.

The effects of childhood cancer can result in family members experiencing a strain within their own lives, faced with the necessity of adapting throughout the journey (Panganiban-Corales and Medina, 2011). Woodgate (2006) highlights that this is a possible explanation as to why many families develop negative sentiments and experience adverse situations regarding paediatric cancer. Bally et al. (2014) supports family system theory stating that families develop an
awareness of the trials they will encounter throughout the journey. This correlates with the findings in Kästel and Enskär (2013) who highlight that participants reported their participation as the most demanding experience of their lives. Which is evidenced in McCaffey (2006) who highlights that once a child is diagnosed with cancer families must face reality involving the prospect of losing the child within the future. Kästel and Enskär’s (2013) study continues to support the concept that immediately after a diagnosis families experience less time as a household and develop a sense of loss within their normal daily routines, thus affecting the entire family system. Nonetheless, there are families who report the experience as a positive outcome, as several parents reported developing an improved functioning within their family associated with a new gratitude for life, their children and time spent as a family (Pai et al. 2007, Zamora et al.,2017).

Kästel and Enskär (2013) along with Long et al. (2013) highlighted that family functioning for some families vary due to the pressure parents put on themselves to re-establish a normal family routine for their children. Recently, Woodgate et al. (2016) emphasised the affliction felt by parents in wanting to care and shield their children from the threats childhood cancer exposed them too. However, Gage-Bouchard et al. (2013) suggested that family environment plays a pivotal element in the parent’s ability to cope and those families who are unable to establish a routine in accordance to their child’s treatment plans were unable to function inconsistently within their lives. Which correlates with the findings in Long et al. (2013) who identifies that family functioning depends on the acceptance of parents. Although, Bona et al. (2014) interestingly points out that many parents, reported they could only function if they still maintained a work life balance and were able to the coordinate the two elements even if this resulted in their work life becoming disordered. Interestingly Peterson et al. (2012) indicated that families dealing with paediatric cancer developed improved functioning levels if they had family members as a source of support and could openly communicate as a system. Van Schoors et al. (2015) highlighted that both parents and siblings reported that they would not have been able to cope and establish a good sense of family functioning without the support and strength from extended family members. Evidence from Creswell et al. (2014) suggests that extended family members are an invaluable resource within paediatric oncology by providing both
emotional and physical support. In some instances, extended family members took over the responsibility of caring for siblings and acquired the duty of arranging appointments, transport to the hospital and taking siblings to school. Overall, those families with a higher functioning system conveyed that they had anticipated nothing less and identified that family was a source of support they couldn’t cope without (Gibbins et al., 2012).

Communication was perceived to be valued highly within families affected by childhood cancer and for some families this element tested their ability to function indefinitely (Kästel and Enskär, 2013). Rimé (2009) identified parental capability to communicate effectively with their children had a permanent impact on the functioning of the family. Patenaude and Kupst (2005) identified that parents who could not talk about their child having cancer left their children feeling isolated, managing their fears alone. Miscommunication can lead to children developing misconceptions and leave them questioning the situation, thus not being able to develop the skills to prevent further emotional distress for themselves. A low-level of communication can often result in good strong relationships becoming fragmented (Lishman et al., 2014). Clarke and Fletcher (2003) identified the communication received from the ill child’s health care provider played a pivotal role in the parent’s ability to cope and function therefore, communicate effectively with their children. However, Kästel and Enskär (2013) disputes that medical guidance often created insecurity for families creating a sense of lost control whilst as the same time gained a sense of relief through their medical expertise. Nonetheless, Gannoni and Shute (2009) identified that even though parents had access to advice and support groups which benefited the family, many did not use the resources as they wanted to distance themselves and reduce time spent within the hospital.

Pianta and Marvin (1993 cited in Popp et al., 2014) stated that family functioning and attachments formed are disrupted when a child is diagnosed with an illness and has an impact on the attachment and care provided. Intriguingly, Nielsen et al. (2012) identified that sibling relationships with parents were just as unsettled compared to the child diagnosed with cancer, especially as they share the same bond with parents. The difference in the level of attachment experienced by
siblings can be related to Bowlby’s ‘attachment and maternal deprivation theory’ (1907-1990 cited in Becket and Taylor, 2010) which focused on the behaviour and effects of attachment changing linked to separation and loss. Bowlby and Ainsworth (cited in Bretherton, 1992) documented that even though parents (mothers mainly) were still physically nearby the secure base they once had often became depleted and there was no longer an attachment with the primary care giver. Supporting this theory Radke-Yarrow et al. (1995) identified that an insecure attachment in parent-child relationships dissolved the functioning of kinships within the family. Parents who struggled with the diagnosis of childhood cancer identified with depressive symptoms often encountering a problematic period with their children in relation to an attachment thus damaging their family function (Long et al., 2013). Moreover, Lane and Mason (2014) highlighted that siblings reported being isolated from their immediate family when their sibling was diagnosed with cancer. Siblings recognised their needs were not likely to be acknowledged because their role altered throughout the journey, especially as some siblings were expected to provide care and support (Bishop et al., 2015)

Similarly, Music (2010) identified that siblings were at greater risk when dealing with childhood cancer as it affected their needs which in some cases were often overlooked. Thus, influencing the relationships and attachments made within the family and the quality of life for individuals. Furthermore, Popp et al. (2014) emphasises that if parents do not implement coping mechanisms this only intensifies the despair and disorder which families experience whilst dealing with childhood cancer. This supports the findings in both Kästel and Enskär (2013) and Long et al. (2013) who identify that siblings and family functioning are affected tremendously when a family is dealing with paediatric oncology.

**Resilience**

Resilience is a common theme which is presented by many individuals dealing with a diagnosis of childhood cancer. Hilliard et al. (2015) identifies resilience within paediatric health and psychology as the aptitude of the individual expressing their well-being related to their health status. Even though they encounter challenges from their circumstances individuals can overcome the trauma which only strengthens their ability to endure risks. Thus, reducing their susceptibility to life changing events consequently becoming self-efficient.
(Lishman et al., 2014). Conversely, Bowes and Jaffee (2013) highlight that resilience is not an individual characteristic developed by everyone but is a concept characterised by continuous change. Robinson et al. (2007) supports this concept by identifying that some individuals do struggle to become resilient regarding a crisis involving the shattering diagnosis that they themselves have cancer or a young member of their family has cancer. Robinson associates this concept with individuals who have high amounts of conflict and disorder within their family system. Therefore, causing children to develop problems with adjusting to the ordeal, resulting in some not developing a resilient outlook (Van Schoors et al., 2015).

Bronfenbrenner (1979 cited in Goldstein and Brooks, 2013) and Gottlieb (2007 cited in Masten, 2016) maintain the theory that resilience is developed on a bi-ecological system perspective. The theory is based on a multiple layer of interactions such as genetic factors connecting to the wider community, education and employment settings. The multiple interactions affect the experiences of an individual which helps them develop a framework to evolve and strengthen their resilience (Green et al., 2004, Gudmundsdóttir et al., 2011). This theory validates why some individuals stay positive and develop resilient behaviour even though they face adversity within lives associated with paediatric cancer. Which correlates with the findings in Creswell et al. (2014) who identified that families with a good social support had higher levels of resilience associated with their mental health.

Rosenberg et al. (2014) studied resilience in parents of children diagnosed with cancer identifying that individual parents associated resilience with being strong-willed to overcome the difficult period for the sake of their children. Maintaining the evidence produced in Phipps et al. (2015) who highlighted that resilience was an enduring element for patients and their parents who influence their children’s aptitude to become resilient Southwick et al. (2014) argue that resilience is not a measurable concept and is formed through an individual’s response to stress and trauma which is in perspective with their relationships within society and culture. Supporting this theory Hilliard et al. (2015) states that resilience has become a broad concept which can be reflected to the different variables used to quantify...
the concept which has created difficulty to integrate findings. Evidence does illustrate that children and their parents dealing with childhood cancer do develop resilience developing a content lifestyle despite their health status (Phipps et al., 2015).

An alternative view be associated with Snyder’s theoretical framework founded on hopefulness. Hope theory (1989 cited in Germann et al., 2015) is evident in several of the coping strategies promoted by medical professionals to aide children and their families to cope with their journey of being a paediatric patient. Relating to Lerwick’s (2016) framework for paediatric medical professionals identifying the strengths of each individual family member to reduce stress levels and aid resilience. Woodgate and Degner (2003) support this theory highlighting within their research that children and family members must develop a sense of hope and spirt to be able to survive the journey of paediatric cancer. However, this does contradict the finding’s in Kästel and Enskär (2013) who identified that parents and family members wanted to remain realistic in their outlook whilst dealing with childhood cancer. Which could suggest why some families faced communication issues with health care professionals.

**Caregiver psychological impact**

Family members especially parents do experience a strain on their psychological well-being when their child is diagnosed with cancer, however current literature highlights that the impact does vary for children and parents (Okado et al., 2016). Demirtepe-Saygili and Bonzo (2011) highlighted that parents with a child diagnosed with cancer were more likely to experience a reduced mental health status because of experiencing increased levels of stress, anxiety and depression, for some parents this resulted in them developing post-traumatic stress disorder (PTSD). Litzelmann et al. (2011) highlighted in theory that caregivers of paediatric patients experienced increased stress levels resulting in their overall mental health deteriorating. This relates to the findings in Phipps et al. (2015) who identified that parents reported developing psychological distress from being a caregiver of a child with cancer however this did vary on when the child was diagnosed with cancer and the level of stress experienced. The findings
identified that the experience for parents justified their amplified levels of post-traumatic stress symptoms (PTSS) and increased their probability of PTSD.

The caregiver stress model developed by Pearlin et al. (1990 cited in Demirtepe-Saaygili and Bozo, 2011) identified the caregiver role as a complex position which is influenced by several different factors. Factors such as age, relationship to the patient, the amount of time spent providing care, and socioeconomic status which collectively has a lasting impact on the psychological distress experienced. This supports Creswell et al. (2014) findings that there is a correlation between financial worries and caregivers developing an increased level of psychological distress. Similarly, previous research emphasises that siblings and caregivers of paediatric patients with a lower economic status developed a reduced quality of life (Karlson et al., 2013). However, finding in Phipps et al. (2015) identified that demographics did not influence the psychological impact of caregivers. Which restores Taylor et al. (2001) evidence which highlights that parental reactions are different for everyone, which significantly affects how they cope mentally with the increased stress levels associated with their child having a life-threatening condition. Recent evidence developed by Curtis et al. (2016) detects that some parents do struggle mentally with what their role as a caregiver means during their child’s diagnosis of cancer. Which supports that it might be associated with distress and bewilderment because their level of responsibility has been reduced as medical professionals take over the liability in providing and protecting their child’s health and well-being (Kästel and Enskär, 2013). Howard-Sharp (2015), Wiener et al. (2016) identified that parents are more likely to disregard their own health status when their child is diagnosed with cancer thus increasing their susceptibility to develop psychological distress. Which reinforces Long et al. (2013) study highlighting that parent psychological distress has a direct impact on their children’s cognitive development which permanently influences them individually throughout their lives. As siblings reported a decreased amount of control within their lives as their parents become more controlling when a sibling was diagnosed with cancer. The findings are consistent with current research produced by Okado et al. (2016) who highlighted that the decreased autonomy in children’s lives had a direct link to parents developing anxious behaviour thus
reducing their child’s independence, influencing the decisions made as a family system.

Parental Perspectives
In contemporary society, sociocultural expectations govern parental gender roles which influence the conduct of parents and how they cope with their child being diagnosed with cancer (Carter and Mandrell, 2013). Furthermore, Jones (2007) identified that mothers commonly provide the care for the child with cancer, putting all their attention and effort into improving their child’s health status. Highlighting that mothers and fathers become increasingly fixated on what is expected of their gender when dealing with childhood cancer. Macdonald et al. (2010) conducted a systematic review comprising of 45 articles dated from 1988 until 2009 focusing on parental perceptions of their experience involving childhood cancer. Interestingly they highlight that within these articles a total of 2374 parents were involved combined, however only 25% (583) of these were men. Whereas 75% (1791) of participants were mothers, illustrating that even though researchers identify parental perceptions, it realistically comprises of maternal perceptions. Which correlates with the findings and the gender of the participants in all four studies selected to be analysed (Creswell et al., 2014, Kästel and Enskär, 2013, Long et al., 2013, Phipps et al., 2015). Which can be associated with Talcott Parsons theoretical framework comprising of the division of labour involving sex roles within family life. Which identifies mothers as the parent who provides emotional and social support for their children, whereas father’s responsibilities comprise of financially providing for the family (Giddens and Sutton, 2013). However, Bennet Murphy et al. (2008) identifies that there is a difference in the expectations of parents as they highlighted that in some cases fathers can cope with the time spent working additional hours whilst still managing to increase the time spent with the ill child. Although Long and Marsland (2011) highlighted that mothers face a battle with themselves relating to being guilty, because they must divide their time between their child ill in hospital and healthy children at home.
Summary

In summary, the current themes have identified that families as a unit are affected by childhood cancer. However, the research highlights that each family is affected differently even though many agree that the experience is a very trying phase for family life. The study is relevant for medical professionals in helping families cope with the diagnosis of childhood cancer highlighting the areas which families struggle the most throughout their journey such as mental health. A positive aspect of the findings can be directed towards siblings and parents who need more help to cope with the effects of childhood cancer. A limitation of the findings can be associated with the country the research was produced in as three out of the four articles were conducted within the United States of America. Which is a country known for its private health care system which questions the external validity of the research (Moule and Hek, 2011). However, a positive aspect of this study can be associated with the findings which do holistically provide an insight to how families cope with childhood cancer incorporating the dimension of family life. Illustrating that family members do struggle individually but as unit aspire to overcome the traumatic experience together.
Chapter 5. Reflection

From the beginning of this process I have overcome much anxiety that I could not produce a dissertation, often worrying over not being able to cope with the amount of the work and dedication required. However, through conducting the research I have overcome many of my doubts and enjoyed the experience concerning the ramifications of childhood cancer on family life. Through this experience, I have learnt a great deal involved with researching articles and themes which have been identified within paediatric oncology. At the beginning, I did struggle with keeping focused as various articles were of great interest but not entirely relevant to the study which wasted relevant time. Through conducting the research surrounding the topic it has highlighted the importance of family life involved with the care and support offered by friends, family and communities. Highlighting that family is a system which is often taken for granted but provides love and support regarding the demanding situations. I never comprehended how important child-parent relationships were in a family and how they influence the ability to cope and becoming resilient when faced with traumatic events. The results have shown me that professionals need to incorporate parents and siblings (dependent on age) when communicating about the ill child’s health treatments and identify where parents are struggling. Furthermore, through conducting the desktop study it highlighted the importance of ethical principles involved which helped me identify articles of good relevance. I have learnt a great deal regarding childhood cancer and the impacts it has on family life but identified that parents want to overcome the distress through improving family life.
Chapter 7. Conclusion and Recommendations

The central aim of this research design was to investigate ‘How are families affected by childhood cancer?’ The review provides insight into how individual family members affect one another’s experience of coping with a traumatic event within a family unit, which focuses on the strengths and weakness of each individual. The research identified that families are affected negatively by childhood cancer which can be linked to psychological distress of a caregivers, sibling attachment to parents and the financial strain experienced. The review has helped identify the specific areas of concern where families need more support and resources which can help medical practitioners, other health care professionals to understand the tribulations families experience.

The literature review provided a detailed overview of the impact the initial diagnosis has on the child diagnosed with cancer whilst informing how this influenced the parents and sibling’s ability to manage the long journey ahead. Findings illustrated that even though in western culture there is emphasis on gender equality within society, there are set expectations of parents associated with their gender and the provision of care they provide for their children. Additionally, these findings were not just located within articles analysed within the review but across the area of paediatric oncology which needs to be reviewed and further research need to be conducted. Family functioning was a current theme identified and explored in detail, however more research is required into professional and parental communication. As this area influenced both parents and children’s experience of managing childhood cancer.

Through completing this review, it highlighted that research is constantly being updated and reviewed which is compliant with the treatment methods used within paediatric oncology. The use of a mixed methods approach within the data selected included different demographics of the population, which illustrated that families do need more support, but is dependent on the resources accessed.
However, the researcher does acknowledge that this is an area which needs more research and dedication to help individuals cope within paediatric oncology. The study does illustrate the negative effects of childhood cancer focusing on siblings which influences their cognitive development impacting their quality of life.

Further research is needed specifically focusing on the different cultural and socio-demographics to examine the wider context of paediatric cancer and the influence it has on family life. Future studies need to direct their attention to extended family members, investigating how the impact of childhood cancer affects their lives which will improve the holistic understanding of the implications cancer has. Many families experience childhood cancer and recovery rates are increasing continuously however, resources and support should be directed towards the family as a unit. In addition to providing help for each individual member to meet their needs and guide them during the journey based on a range of influential dynamics.
Reference List


Wednesday, 23 November 2016

BSc (Hons) Health & Social Care
Cardiff School of Health Sciences

Dear Applicant

Re: Application for Ethical Approval: How is parenting affected in a family when a child is being treated for cancer?

Project Reference Number: [redacted]

Your ethics application, as shown above, was considered by the Applied Community Sciences Ethics Panel on 11/23/2016.

I am pleased to inform you that your application for ethical approval was APPROVED, subject to the conditions listed below – please read carefully.

**Special Conditions of Approval**

1. Change the start date

Please confirm by email to cahsethics@cardiffmet.ac.uk that you understand the “special conditions of approval” and that where changes to the information sheet, consent form and/or procedures are deemed necessary, these have been carried out as requested. If you are a student – your supervisor must do this.

**Standard Conditions of Approval**

1. Your Ethics Application has been given a Project Reference number as above. This MUST be quoted on all documentation relating to the project (e.g. consent forms, information sheets), together with the full project title.

2. All documents must also have the approved University Logo and the Version number in addition to the reference and project title as above.

3. A full Risk Assessment must be undertaken for this proposal, as appropriate, and be made available to the Committee if requested.

4. Any changes in connection to the proposal as approved, must be referred to the Panel/Committee for consideration without delay quoting your Project Reference Number. Changes to the proposed project may have ethical implications so must be approved.

5. Any untoward incident which occurs in connection with this proposal must be reported back to the Panel without delay.
6. If your project involves the use of samples of human origin, your approval is given on the condition that you or your supervisor notify the School of your intention to work with such material by completing Part One of the form entitled "Notification of Intention to Work with Human Relevant Material or Human Bodily Material" which must be obtained from the PD (Sean Duggan), BEFORE any activity on this project is undertaken.

This approval expires on 11/23/2017. Please set a reminder on your Outlook calendar or equivalent if you need to continue beyond this approval date. It is your responsibility to reapply / request extension if necessary.

Yours sincerely

[Signature]

Professor George Karani
Chair of Applied Community Sciences & Protection Ethics Panel
Cardiff School of Health Sciences

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Cc: Burrows, Dan

PLEASE RETAIN THIS LETTER FOR REFERENCE