

## **The hidden cost of cancer: the siblings' story, a mother's narrative on how three of her children journeyed through their 14-year-old sister's nine-month journey from ill health to death and beyond**

### **Abstract**

The siblings of children diagnosed with cancer can get lost in the cancer journey. Through a mother's eyes, this paper examines the issues faced by three siblings when their teenage sister is diagnosed with and dies of cancer. It focusses on the impact their sister's illness has on their educational, social, emotional and communication skills. Each sibling not only had their own unique set of needs but this paper argues that the term 'cancer survivor' should also be extended to the siblings as they comprise an intrinsic part of the family's cancer journey. The paper calls on professionals to adopt a holistic approach to reduce the impact that childhood cancer has on the siblings and it highlights the far-reaching consequences of not properly supporting the siblings during this time.

**Keywords** - Cancer, quality of life, family, siblings, mental health

# **The hidden cost of cancer: the siblings' story, a mother's narrative on how three of her children journeyed through their 14-year-old sister's nine-month passage from ill health to death and beyond**

## **Introduction**

This study utilises a mother's narrative of how the diagnosis of cancer of one of her four children impacted the three siblings' educational, social, emotional and communication skills both during treatment and after her death. The aim is to draw lessons which may enable service providers to better support the siblings in families where a child is diagnosed with a chronic illness. This paper is a sister study to that written by the author on the mother's account of her fourteen-year-old daughter's nine-month journey from the diagnosis of cancer to her death (Bara, 2017).

Cancer Research UK (CRUK) states that one in 500 children in the United Kingdom will get cancer between the ages of 0-14, which represents 0.5% of all cancers diagnosed. According to CRUK there are over 200 types of cancer, treatment times range from 1 month through to 3 years or more, depending on the type of cancer. During this time families incur not only a financial cost but physical, social, emotional and psychological costs. Joubert et al (2015) stated that 'cancer patient management has unique characteristics compared to other chronic conditions', in part this is due to the complex and diverse nature of treatment and the spectrum of effects it has on the patient. Cancer treatment is complex and requires specialist centres, depending on the cancer type patients may be required to travel across county/state lines and/or international borders. Considerable periods of time might be spent in hospitals, not only for treatment but also for routine post-treatment monitoring of the spectrum of side effects that paediatric cancer patients incur. Appointments and treatment further contribute to the disruption in family routines and finances, and can impact negatively on the whole family's quality of life (Bara, unpublished 2017).

This paper emerged from a larger study entitled 'Do parents feel that the academic performance, and social, emotional, communication skills of their children with life threatening/limiting condition (LTLC), as well as their siblings, are affected by the condition?' (Bara, unpublished 2017). Using a thematic analysis (Braun and Clarke, 2006) of the larger study, it was felt that this simple case study encapsulated the issues that were presented in the wider study. The advantage of using this case study is that it enabled the researcher to look deeper into issues and better understand complicated situations (Ashley 2017). This paper highlights the fact that the mother viewed the siblings as an intrinsic part of her family's cancer journey and she saw the impact that cancer was having on each child's education, social, emotional and communication skills. It is acknowledged that one should not draw generalisations from a single narrative, yet there are still merits in using this account. It not only reflects issues that were discussed by other families interviewed under this project but this account was particularly pertinent as the sister died just nine months after diagnosis. As such, this case clearly illustrates the challenges that parents of chronically/ terminally ill children face.

The mother acknowledged that the interview schedule allowed her a structured reflection on the journey she took with her children. The interviews could also be seen as empowering her during bereavement process; the mother clearly stated she felt lessons could be learned from her family's experience and she wanted them shared.

The phrase 'cancer survivor' is commonly used by professionals and people to describe a person diagnosed, living with or beyond cancer. There are two issues that arise from this study; the first is that society should acknowledge that siblings are an inextricable part of the childhood cancer journey, they will live with and beyond the diagnosis of their sibling's cancer and may even play a key role in their sibling's treatment, as such they should also be considered cancer survivors. The second issue is that a holistic approach should be taken by professionals in order ensure their needs are met when they are at a very vulnerable time in their lives. The study draws out the need for professionals to

work and interact with the whole family to in order to support them through the cancer journey. It clearly demonstrates people's actions can either support or exacerbate a traumatic and stressful situation. Therefore, it is vital that the professionals and friends listen to and hear what is being communicated to them. The discussion now moves on to consider the literature in this field.

## **Literature review**

Cancer is perceived by many as being a chronic or life threatening, therefore requiring a swift response time and it is this that makes it a unique chronic illness (Bell and Ristovski-Slijepcevic 2013). When a person is diagnosed and treated for cancer they will go through a series of changes either physiological and or psychological, as such, they will have a spectrum of immediate and late effects (American Cancer Society). Yet cancer survival can mean many things; clinicians commonly use it to describe a person who is five years post diagnosis and who is cancer free but this definition is challenged by physician Fitzhugh Mullens (1985) who divided the cancer journey into three stages: acute, extended and permanent. Cancer survivorship is not just about the length of time a cancer patient lives for, but about their quality of life during treatment and beyond (Leigh 2007). Therefore, the National Coalition for Cancer Survivorship's (NCCS) definition of cancer survivorship will be used. The NCCS defines cancer survivorship as; 'living with, through and beyond a cancer diagnosis.'

Lederberg and Holland (2011, p.11-12) recognise that different members of the family react in different ways to the diagnosis, treatment and death of a family member and they too could be defined as cancer survivors as they may live through the three stages cancer survivor. In some instances, family members may be a direct part of the treatment process, with bone marrow donation being one example. Bone marrow donation can be a lengthy procedure leaving the donor fatigued and bruised (CRUK, 2015). There are ethical issues that surround the testing for and harvesting of tissue samples from a sibling if they are minors and, in the United Kingdom, the procedure to gain consent follows a code of practice produced by the Human Tissue Authority. Bendorf and Kerridge (2011) found that donors may subsequently feel abandoned following the donation procedure, when the family's attention shifts from them to the recipient during the recipient's long recuperation process. They also note that the donor may feel responsible for the outcome of the transplant itself.

Childhood cancer survivors often need to be close to their parents to feel in control, moreover they may want to see their siblings and or friends regularly but hospital or ward policy may not cater for this need (Darcy et al 2014). Restricted access to patients may cause real conflict between the various parties causing additional social and emotional strain for the family.

Alderfer (2009) conducted a systematic review of the 'psychosocial adjustment of siblings of children with cancer'. She found that one or more parents will focus predominantly on the child with cancer resulting in a decrease in social activities as the parents may not be able to take the children to these key events. Houtzager et al (2005) found that more than half siblings aged between 7-18 showed fewer 'positive emotions' within the first month of their sibling being diagnosed with cancer. Both Houtzager (2005) and Alderfer (2009) found that females had greater social issues than males, with Alderfer (2009) stating that the adolescents struggled the most. In an earlier paper about siblings of cancer survivors, Alderfer et al (2003) report that siblings can show signs of and/or experience problems similar to post-traumatic stress.

The act of communication has many different mediums including oral, written and body language and siblings may find it challenging to understand and communicate the feelings they have which may result in them keeping them hidden (Kuo and Kent 2017). Drawing is a communication instrument that can help childhood cancer survivors communicate how they are feeling during their journey (Rollins 2005). Art therapy is one way in which a patient can become active in their treatment process and express their feelings (Malchiodi 1998), it allows people to process information and their emotions (Lusebrink, 2004).

Alderfer et al (2010), concluded that a holistic approach should be taken whereby the family, education providers and clinicians should work together to create a supportive environment for the siblings, in order to support them through their readjustment to having a sibling with cancer.

## **Methodology**

A qualitative, narrative and free associative methodological approach was used for data collection, as it is appropriate for researching individual experiences including bereavement (Hollway and Jefferson, 2008; Goldie, 2011). Participants in this research were self-selecting via an advert posted on a social media forum, where parents of children with cancer discuss pertinent issues. The advert was posted only after permission had been granted from the forum moderators and ethical clearance had been obtained. The names of all parties have been changed, and the locations and dates have not been stated to maintain anonymity.

The University of East London Ethics Committee approved the research project and consent was given by the participant to use excerpts from the interviews covering all topics.

The author has experienced cancer from multiple perspectives and at different ages and stages in his life. He has been both a service user and deliverer (as an educator) and as such, he has an insider's perspective of the issues. In his first role as a qualified teacher, he taught a child who had just lost a parent to a brain tumour and supported them through part of the grieving process. Later, in 2012 the younger of his two children was diagnosed with an aggressive brain tumour at the age of two and a half. While his daughter was going through treatment, he worked as a home school tutor working with a child who was also being treated for cancer. He met the child's two teenage siblings and sat with the whole family at times, discussing the issues they were facing. Furthermore, the author is an active member of the childhood cancer community. He is therefore conversant with the culture, norms and language that are used by the paediatric cancer community and this is reflected in this paper. Due to these experiences, the author identifies with Dwyer and Buckle (2009) and acknowledges that, as an insider, his life experiences shapes and informs his research, making him a different type of researcher.

A case study research was conducted entitled 'Do parents feel that the academic performance, and social, emotional, communication skills of their children with a life threatening/limiting condition (LTLC), as well as their siblings, are affected by the condition?' (Bara, unpublished study). This interview, with Jane, stood out from that study due to the age range of the siblings, the emotional demands placed on the family and the reactions that Jane, a mother of four, recounted the reactions of three of her children to their sister's cancer journey. The interviews took place just before the second anniversary of the child's death and the researcher had been in contact with Jane three months prior to the interviews, which were conducted over several weeks for logistical reasons. Research questions were designed and developed in order to answer the key research question, the questions were piloted and refined with three childhood cancer parents, following the method used by Ashely (2017). Nine months after the initial series of interviews, the mother got in touch to update the researcher on the progress of the children and this additional information was incorporated into the paper.

The interview can be considered a biographical account within the larger case study of Jane's life story (Tedder 2017, pp 287), it should be acknowledged that her answers were biased and subjective. The researcher and Jane shared similar cultural experiences, the culture of being cancer parents. Thus, a high level of trust was given to the researcher and a high level of respect was given to Jane (Bassey, 2003). In places the discussions transitioned from research interviews into what may be interpreted as a conversation between two parents who were sharing similar experiences. As such, the researcher was able to better understand Jane and what she was describing (Tedder, 2017). It is acknowledged that Jane may have adapted the story over time. Furthermore, the story may have changed as the questions may have challenged Jane to reassess her account and influenced future answers.

Throughout the interview process the researcher verified with Jane if she was happy to continue, due to the personal nature of the research. She clearly explained that she was engaging in the research as a cathartic experience and she may have been selective in how she recounted her children's experiences. The author recognises that they have collected, interpreted and presented data from the perspective of an insider. The author acknowledges that these circumstances create a position of bias but they also allow for issues to be explored with increased depth and insight. Notes were taken during the interviews which were then transcribed, the researcher acknowledges that silences were

challenging to analyse (Tedder, 2017). It could be argued that the mother's narrative was anecdotal, however, this interview comprised part of a larger study and demonstrably highlighted the issues that parents in the wider study were discussing.

Thematic analysis (Braun and Clarke, 2006) was used to investigate the case study; this method allowed the author to identify and investigate patterns that arose from the data. Key themes to emerge from the case study were:

1. The siblings are a fundamental part of the cancer journey and each sibling's journey is unique.
2. The ethical and emotional issues and pressures that cancer places on siblings.
3. The mental health issues that may be created or appear as a result of a sibling being diagnosed with cancer.

Narrative interviews (Gray, 2009) were used to collect primary data. This method was used by De Cinque et al (2006) during their research of the support that bereaved families received after the death of a child from cancer. It is acknowledged that the aims were different but it could be argued that the emotional experience was similar. While writing the research, the author referred to both the transcriptions and the audio recordings.

## Results

### **An overview of the United Kingdom National Health Service**

Each of the four countries that make up the United Kingdom (UK) has their own National Health Service (NHS). While treatment is free across the board, if a specific procedure is not available in the person's home country and they are required to travel to a different UK country for treatment, they may be subject to the different service level agreements and lose certain entitlements.

### **A family overview**

The household at the focus of this article comprised two parents, both of whom worked, and four children: Susan, in her mid-teens and attending secondary/middle school when she was diagnosed with cancer; Sarah, the eldest child, had existing mental health issues but had left home and was attending university; Tom was in his early teens and attended secondary/middle school; and Katy who was in primary/elementary school. It should be noted that all three younger children attended a faith school. Very little was mentioned by Jane about the role of the father and, while there was an extended family network, she also did not discuss their role.

### **Susan – her journey from illness to diagnosis, treatment and death**

It was evident throughout the interviews that Jane believed Susan held deep religious convictions; she actively took part in daily religious practice and had a good relationship with her siblings. Jane repeatedly reported that prior to Susan's illness she enjoyed supporting her peers, the younger children at her school and was active in the many youth groups. Susan came across as a vivacious, caring person who, as Jane reported, "would express her feelings".

For four months prior to Susan's diagnosis of cancer she had been unwell, and this resulted in many tests which required travelling for up to four hours at a time for each hospital visit. It was identified that Susan had a rare form of cancer and required a bone marrow transplant. This placed a unique strain on the family, as the siblings were potential donors (this event will be reported in the results as a separate event). Susan needed to travel to a different country in the UK for treatment and there was very little time to prepare the family for the rapid change. Susan needed to be isolated with only three non-medical, named people allowed physical access to her. The decision was made that it would be her mother, her father and her boyfriend, whilst her siblings would be unable to visit. While Susan was entitled to medical treatment and educational support in the country she was treated in, she was not entitled to mental health services under the regional service level agreements. Ultimately the treatment was not successful and within nine months, Susan passed away.

### **Jane**

Prior to Susan's illness, Jane had a career. When Susan became ill so rapidly, the family found itself in crisis, which restricted Jane's ability to work and ultimately forced her to resign, impacting significantly on the family finances. While Susan was going through treatment, Jane recounted that *'not only did I have to support Susan but also my other children'*. However, it became clear from different segments of the interviews that Jane's ability to care for her whole family was also reduced, resulting in a change of family dynamic. The family's routines were disrupted further still when Susan moved away for treatment. Jane explained that while extended family provided day-to-day and weekly support, they *'did not replace the support that I provided for the family'*.

Jane described herself as having a *'very close relationship with Susan'*. It was evident throughout the interviews that Jane felt they shared the same values, particularly from a religious perspective, which appeared to be one of the cornerstones of their relationship.

Jane went back to work after Susan's death and explained that she made a conscious effort to balance work and home life and to create routines, yet she said that she found it hard to support her children. Jane also commented that she felt she had lost two children; Susan through death, and her son, Tom, as he refused to attend family events during the first few years following Susan's passing. Jane finished by saying that *'The help and support that we have had from the relevant charities has*

*definitely played a significant part in helping us to rebuild our family life. I'm still grieving, I will always be heartbroken, but our family isn't fractured'.*

**Sarah (Susan's older sibling)** – Sarah was in her late teens and Jane reported that she had been a gifted student all her life yet had a history of mental health issues prior to Susan's illness and did not express her feelings. Sarah had a good relationship with Susan. She was living and studying away from home prior to Susan's diagnosis. Jane discussed the dilemma she faced as a parent and that she did not want to worry Sarah about Susan's ill health but when Susan was diagnosed with cancer Jane explained that they rang Sarah to 'break the news'. A few days later Sarah was found collapsed in the street, with memory loss and a broken limb. Sarah was subsequently required to move back home, interrupting her studies. Jane explained that at this time Susan was still being treated in her own country but the treatment was taking place in a hospital many hours away. Despite this, Sarah was demanding her parents' attention, asking them to do small things that she was capable of doing herself. Several weeks later Susan was diagnosed with an aggressive cancer and she was required to have a bone marrow transplant, by which time Jane explained that Sarah had become more independent and was going on work experience for the summer.

It was explained that the educational establishment where Sarah was studying had been made aware of the family's situation and they offered support. Sarah chose to defer a year of her studies but this break then impacted on her educationally, socially, emotionally and financially. After Susan's death, Jane explained how Sarah's mental health stabilised and that she took anti-depressants to assist in that process. Sarah returned to her studies in the next academic year and was doing very well.

Jane discussed how Sarah was hostile towards religious beliefs prior to Susan getting ill. This did cause tension within the family; however, Sarah became more accepting of religious beliefs after Susan's death which helped them all to reconcile their feelings towards each other. Jane disclosed that while charities were involved with the family and they did offer support to Sarah but she rejected the help. Finally, Jane explained that even years after Susan's death, Sarah admits that she has not yet dealt with her grief.

### **Tom, Susan's younger brother**

Tom was several years younger than Susan. Jane explained that he was above the UK national average academically, yet from a young age had been identified as having social, emotional and empathy difficulties as well as an obsessive personality. When asked if he had been diagnosed with special needs, the answer was negative. Jane commented that she suspected that he had Asperger's and after Susan's death Jane said that she believed this even more strongly due to his behavioural changes during her illness. Jane went on to explain that the referral waiting time for diagnosis was very long in her area, furthermore she had also decided to change Tom's school in order to maximise his potential in his areas of interest.

Jane said that whilst the school did not see a change in his academic performance while she was away, they did report a change in his behaviour. They felt that this had happened because routines had changed at home and that Jane was the one who enforced the structure. Jane explained at different points and in different ways during the interviews that they did not see a further impact on his behaviour upon Susan's death, and that once structure was reinstated at home, Tom's behaviour returned to how it had been previously.

It was explained numerous times that Tom had good information technology skills but his use of the computer had to be monitored and restricted by his mother. When Jane was away with Susan, these checks and controls were not rigidly enforced. Upon Jane's return from hospital, she explained with a tone of frustration that when she tried to reintroduce the restrictions, she faced "significant resistance" from Tom, including threats to self-harm. Jane explained that, at this time, she did not have the



emotional energy to enforce the rules. Following Susan's death, Jane described how she saw a change in Tom's personality; one example was of Tom spending more time in his room on a website where he could develop characters and worlds and communicate with fellow developers. Jane explained that she did not know if his behaviour had changed because of the trauma of Susan's death or his "special needs". She discussed how a company that produces software invited Tom and several other people to do a short internship with them. After numerous checks that the company was legitimate, Tom spent a period at their headquarters which resulted in a further positive change in his social, emotional and life skills. While describing this period of Tom's life, Jane sounded relieved and excited. Finally, it should be noted that Jane discussed how Tom's school offered him support after the death of Susan, but he refused and Jane felt that he was not dealing with the issues.

### **Katy – Susan's younger sister**

Katy was the youngest child in the family. Jane could not stress enough how close Katy and Susan had been, giving many examples throughout the interviews of their strong relationship. It was explained that Susan had played a significant role in caring for Katy which enabled Jane to help Tom. It came across that Susan was more like a surrogate mother than a big sister. Jane explained that she tried to take Katy along to hospital visits but at times it was not logistically possible. Drawing upon several different segments of the interviews, the rationale seems to have been to include Katy in the process so that she could gain an understanding of what was happening. Due to Jane's extended stay in hospital abroad with Susan at the start of the academic year, Katy did not receive the support her mother usually gave her. Jane explained with anguish in her voice that she always plaited Katy's hair for her before school but this was subsequently done by Jane's friends on their way into school. Jane also missed Katy's birthday causing both her and Katy great distress.

When Susan returned home, Jane explained how Susan and Katy became inseparable. They would stay together until bed time, separating only when Katy went to school. Jane described how Susan had been having regular outpatient appointments and returning home afterwards. This had been the routine for several months when suddenly, Susan did not return home from what was expected to be regular appointment. Instead, she had been admitted to an intensive care unit (ICU) and was placed on a ventilator. Jane did not state, explain or infer that this was the palliative care stage in the interview, yet she explained that Susan died two weeks later. Throughout the two week period whilst Susan was in the ICU, Jane said that the rules of the hospital meant that Katy, as a minor, was not allowed to see her. Jane described the staff's intransigence and she felt that they did not fully understand the social and emotional needs of either Susan or Katy. It was evident in Jane's voice that this lack of access was distressing. When it became clear that Susan would not survive, Katy was finally allowed to see her sister and Jane remembered: *'several hours later, Susan's ventilator was switched off'*.

Jane explained how Katy's school created a support program which included circle time sessions themed around loss. They created a box that she could put items in that were special to Susan and herself. The school offered one counselling session but following this one conversation, the councillor felt that Katy did not need further therapy as she had been included in Susan's whole cancer journey, as such, Katy was not offered any more support. Two years on from Susan's death, Jane shared that Katy *'still spends as much time as possible in her bedroom, with the exception of when Sarah is home'*. She also disclosed how she and Sarah have found sketches drawn by Katy of a person self-harming. It should be noted that the researcher was contacted by Jane one year after the interviews that this article is based on, to discuss how Katy's mental health had deteriorated further. Jane had found a group that explores grief through art, which Katy had attended for 'a number of weeks', and it was through art that Katy was starting to explore how she felt about Susan's death. Jane went on to explain that as a result of the evident deterioration in Katy's mental health, she was also offered and received counselling from another charity for six months but it was unclear what effect that counselling had. Jane discussed how Katy's academic performance remained *'consistent'*. Katy has subsequently transitioned schools, moving to the same secondary school that Susan had attended. Jane explained that the school was aware of the family history and had *'provided solid support and she is performing well'*.

## **The bone marrow transplant**

The bone marrow transplant stood out as placing a unique psychological strain on the family as it placed an exceptional set of pressures on the siblings, who potentially held the key to improving Susan's life chances. While describing the events prior to and during the bone marrow transplant, Jane's voice exhibited distress, annoyance and frustration. Jane explained that she received a phone call from a consultant unknown to her, who 'stated' that Susan would require a bone marrow transplant and that they would need to test two of Susan's siblings to see if they were matches, and that this all had to be done as soon as possible. She revealed that she felt that it was *'a harsh and clinical way to deliver the news. It left me in shock as the clinician was a stranger to me and he didn't give me any further facts, support or guidance'*. Jane discussed how she then understood the serious nature of Susan's illness and that the family would be separated for many weeks.

The key challenge was to find a donor and the doctors asked for Susan's two older siblings to be brought in for testing. Jane recalled how this led to three issues for the parents to resolve. The first was that they felt that Katy should be included in the testing procedure for a match which brought them into disagreement with the consultant who felt that, due to Katy's physical age, she would not be *'mature enough'* to handle the procedure. Jane discussed the need for bone marrow testing with Katy and Jane stated that Katy wanted to be tested. The second issue was Tom's maturity levels. Jane clearly explained that while Tom was older than Katy, he was too immature to cope with the procedure and both parents had to persuade Tom to go for testing. Tom was, in fact, a match and Jane stated that her fears were borne out, as he initially did not want to donate. This led to the third issue; explaining to Tom the importance of the donation. Jane described how Susan had overheard Tom's initial reaction, which caused Susan and the whole family distress. Jane went on to say that once the situation was fully explained to Tom and he understood what was at stake, he provided the marrow donation willingly.

Katy went with the family to the transplant unit but she was not allowed inside due to their strict visitation policies. Jane remembered how this caused serious distress to both sisters. Moreover, Jane reported that Susan's last words to Katy were *'see you in a few hours'*, but they did not see each other for another five weeks, as Susan's immune system was severely compromised and only three people were allowed access to her. Jane explained that Susan had decided that those people would be her mother, father and boyfriend. Jane went on to explain that limited access to the internet further exacerbated the stress placed on all the siblings and family.

While Sarah was on a work placement over the summer, Jane recalled that she *'was placing even more demands on me which were nearly impossible for me to fulfil'*. Despite the fact that her husband and extended family were there to meet her demands, Sarah insisted that her mother do the tasks. With a note of frustration in Jane's voice, she recounted that Sarah didn't ask about her sister's health and that Sarah was competing for her attention. The family did arrange for Sarah to visit Susan during the transplant and even arranged with the staff that Sarah could have access to her, yet Jane described feeling *'compelled'* to spend some down time with Sarah while she was visiting Susan but this came at a cost, as Susan was afraid of being alone. Jane then spoke of how the time Sarah and Susan spent together was short but of *'high quality'* and that Sarah's attitude changed towards Susan's position, writing letters of support, encouraging her sister to get better, which Jane has kept. She also strongly thought that Sarah's interaction and communication with the whole family improved following that visit.

## **Three years on: the siblings**

Jane reported that after the third year, progress had been made. She was keen to relay that *'My son has undergone a complete transformation in the past year - he's amazing now! We attended a family wedding... and several relatives commented positively on the progress that all three of our children have made in terms of their character and emotional maturity.'*

## **Discussion**

The aim of the study was to utilise a mother's account of how the diagnosis of cancer of one of her four children impacted their siblings' education, social, emotional and communication skills.

The study found that the siblings were an intrinsic part of their sister's cancer journey and that each sibling's own journey was unique but there were also common themes. According to Jane, all three of the siblings faced challenges with their education, social, emotional and communication skills. These issues were either explained explicitly or implied by the mother. It was not within the scope of this paper to discuss how the mother managed these issues but it is worthy of further research. Therefore, while Susan was surviving cancer as defined by NCCS, it could be argued that so were the family.

Socially and emotionally there was an impact on all three siblings to differing degrees. The family routines that acted as a cornerstone for the children's health, such as eating together, attending weekly religious worship and knowing a parent would be there to watch a school assembly, were disrupted when Susan started to get ill. The oldest sibling, Sarah, subsequently withdrew from university and placed greater demands on her family at a time when they were in crisis, so it can be argued that her social skills detrimentally changed. Tom became more socially isolated from his family during his sister's illness and for some time after her death. Whether this was a result of the change in family routine during the cancer journey or a possible feeling of abandonment or responsibility from being her bone marrow donor (Bendorf and Kerridge 2011), or the impact he felt directly from her illness and death, or a combination of these, was difficult to determine from the interview. It was clear that Katie suffered emotionally as she was not allowed physical contact with Susan at certain times during her treatment and, as a result of the disruption to her birthday, and she chose to withdraw to Susan's room after her death. All of the siblings within study fell within the age range of 7-18, in line with Houtzager et al (2005) and Jane described the siblings as having 'fewer positive emotions'. As there were more female siblings than males, it is difficult to assess whether the sisters had greater social issues than the brother, as found by both Houtzager (2005) and Alderfer (2009), yet Jane did report that both suffered social issues to varying degrees. A seemingly simple thing like not being able to plait Katy's hair before school caused both Jane and Katy emotional distress and this may have led to a change in Katy's behaviour. The behavioural patterns of all three siblings clearly demonstrate that they had to psychologically readjust to the dynamic situation with their sister and this links to the findings of Alderfer (2009) and is clearly demonstrated by Jane not being able to attend Katy's birthday party. It is worth noting that all three siblings may have felt socially and emotionally more isolated from both their mother, as Susan justifiably may have needed to be closest to her parents (Darcy et al 2014).

The communication skills of the siblings adapted to the situation in order for them to cope with the situation. It could be argued that Sarah was causing additional pressure and stress on her family, conversely it could be argued that she was communicating her distress by her very actions and as such keeping her true feelings hidden (Kuo and Kent 2017). Both Tom and Katy chose to isolate themselves in the house at various stages during and after Susan's cancer journey, which may have been their way of keeping their feelings hidden. Jane explained how Katy drew, using art to express her feelings, which may have allowed her to process how she was feeling and understand her emotions (Lusebrink, 2004).

Susan was diagnosed at the end of the academic year and died half way through the next academic year. Two of the three siblings' education was impacted in varying degrees by their sister's illness and subsequent death. Upon reflection, the word 'education' should be replaced with the phrase "impact on the siblings' educational experience" as not only were all three in different educational establishments but all three were in different stages of their education. The common theme was that all were impacted. Sarah, the oldest, left her studies and returned home for the duration of her sister's illness, this resulted in her degree taking one extra year to complete, moreover her peers would have moved on requiring her to develop new relationships. Tom's school reported a change in his

behaviour, while this may not have affect his academic performance this could have impacted how his teachers and peers interacted with him. Katy, the youngest sibling and closest to Susan, presented no change in her academic performance. This could have been as a result of support systems being in place in both her primary and secondary schools which may have pre-empted any issues and in line with Alderfer et al's (2010) suggestions in terms of providing a supportive environment for the siblings. Whilst one should not assume anything from a small-scale study, it might be surmised that the siblings' academic performance may not have been impacted due to the time in the academic year that Susan was diagnosed, treated for and died of her cancer.

What the parents and siblings witness and experience are a fundamental part of the cancer journey. The family's rights and needs should be recognised, acknowledged and considered by all parties who encounter them; this includes hospitals, charities, schools, employers and any organisations that the family is part of. The whole family's voice should be listened to, both individually and as a group. Each person's feelings and needs should be considered, not only in the short term, but over the long term. Once the child with cancer has either survived the cancer as per the standard medical definition of five years, or the child has passed away, the family will still carry on, thereby making each member a survivor.

The term cancer survivor is owned by the patient but from the findings of this research it is clear that siblings are also cancer survivors. They are living with, through and beyond the diagnosis of cancer and in this study, Tom, by donating his marrow, became an integral part of his sister treatment. Therefore, when looking the impact of cancer, one must look at the social, emotional and education impact that cancer has on the siblings in the short term, medium and long term and a multi-disciplinary approach and plan should be developed to support siblings between the ages of 0-18. A review should be conducted on each sibling at the start of their sibling's diagnosis. Their social, emotional, psychological, physical and educational performance should be baselined and this baseline must be reviewed regularly in order to ensure the siblings are progressing at the same level if not at a higher-level pre-diagnosis. This may provide early intervention for any issues that may arise, not only helping the child but also reducing the cost that the diagnosis of cancer brings to the family and wider society.

### **Limitations**

This paper came about from a larger study entitled 'Do parents feel that the academic performance, and social, emotional, communication skills of their children with a life threatening/limiting condition (LTLC), as well as their siblings, are affected by the condition?' (Bara, unpublished). It could be argued that this case was biased as it may appear that the researcher, as an insider, has predefined ideas (Flyvbjerg 2006) on what the responses would be from the mother. However, the limitations of the case study can also be viewed as a strength (Ashley 2017) as it enabled the researcher to examine the issues in depth. This narrative was chosen above the others as it encapsulated the challenges expressed by many other participants from the wider study. For ethical reasons, certain lines of questioning were only followed if the mother stated clearly that she was happy to discuss these. The mother was white British which may limit the ability of the findings to be generalised across parents with different demographic profiles (e.g. gender or other ethnicities). Finally, the mother may have been still be grieving for her daughter, she may have been selective in her narrative on how her children reacted to their sister's ill health and may have want to participate in the study in order to help other families (Decinque et al, 2006). Future studies may consider including additional information such as health care utilization or corroborating information from caregivers.

### **Conclusion**

Due to this intensity, the siblings had to transition between having a healthy sister, to one that was very ill and subsequently dying within nine months. This had a significant impact on the siblings' educational, social, emotional and communications skills.

As the numbers of children and young adults being diagnosed with cancer increases, so the number of siblings being affected by cancer goes up. The challenges, issues and traumas the siblings face may largely go unnoticed and unrecognised and can lead to additional strains and costs being put on the stakeholders who work with them. It is vital that a holistic approach should be taken when a child or young adult is diagnosed with cancer and systems should be put in place to support the siblings throughout the cancer journey and beyond.

It is the author's belief that when society recognises a child's diagnosis, they should also properly acknowledge and accept the pressure the whole family is under. A flexible action plan should be rapidly developed and implemented in order support the whole family throughout the cancer journey. The action plan should be reviewed on a regular basis in order to ensure support is in place during critical transitional periods, to reduce the effects that the cancer journey is having on the siblings and family, thereby improving the quality of lives of the whole family.

I will allow Jane to finish this article with a quote regarding the family's journey:

*'When Susan was alive and well we were very family oriented and had picnics, family bike rides, played board games together, etc. After Susan died it became incredibly difficult to do things together as a family because the sheer act of getting together as a family was a painful reminder of Susan's absence.'*

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