

In my hours of need, I was robbed of my family, friends, beliefs and education.

A mother's narrative on her 14-year-old daughter's nine-month journey from ill health to death.

Abstract

The study utilised a highly qualitative, narrative and free associative (Hollway and Jefferson, 2008) methodological approach to give a mother's perspective of her teenage daughter's 9-month journey from diagnosis of cancer to her death. Cancer is a unique chronic illness that impacts both physically and psychologically. The key findings of this study show that medical treatment alone is not enough and that professionals must understand the impact that cancer and the treatment has on the quality of life (QoL) for the child and how the phrase 'surviving cancer' has different meanings. It highlights the importance that family, friends, beliefs and education have on supporting a teenager and the consequences of denying that access to all stakeholders.

Keywords (8 words) - Cancer, children, adolescents, quality of life, hope, death

Introduction

This study utilises a mother's account of her fourteen-year-old daughter's nine-month journey through cancer, from diagnosis to her death, in order to understand how professionals could better support children's cancer survivorship and improve their quality of life.

The paper explores the different definitions of cancer, what cancer survivorship means, the effects of treatment and how the quality of care is inconsistent. It discusses the physical and psychological impact that cancer has on the body and the issues that children and adolescents face while receiving treatment. Through the mother's narrative, the paper explores how the child's friends, boyfriend, immediate family, religious belief and education supported her through her journey from ill health to death. The paper further shows people and systems that surround the child/adolescent. The paper discusses the limitations of the study and acknowledges that it was written in the wider context of the social impact that cancer has on the family. For ethical reasons all names have been changed. The child with the chronic illness is Susan, her three siblings are Katy, who was a preteen, Tom, who was in his early teens and Sarah, who was in her late teens and attending university. Susan's mother, Jane, was a public sector worker who had to give up work due to the daughter's illness and Susan's boyfriend, Alan, was in his mid-teens. Susan's father was not discussed in depth during the interviews.

According to Cancer Research UK (CRUK), one in 500 children in the United Kingdom will get cancer before the age of 14. Furthermore, CRUK states that there are over '200 types of cancer' and while there are universally recognised protocols for treating certain types of cancers, individuals' treatments do vary. It must be understood the treatment times vary and can last from months to years and as Joubert, Wan, Bhatt, and Chan (2015) stated, 'cancer patient management has unique characteristics compared to other chronic conditions'. It is often not fully understood that the treatment of cancer for a child can take place locally but may also involve travelling across national and/or international borders. The type of cancer

determines availability and locality of resources and services. The support that a child receives will also vary, depending on:

- the facilities at the hospital;
- the co-ordination between multidisciplinary teams and third sector organisations;
- the payment plan/service agreement the child/family has;
- the local/national/international agreements.

This article 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?' It was felt that this series of interviews highlighted the importance and interplay between education and social, emotional and communication needs when a child is facing a life threatening/limiting condition.

While it is acknowledged that one cannot draw generalisations from a single narrative, there are still merits in using this account as it resonates with the other interviews carried out under this project. This narrative was particularly emotive as the young person died. It was, in part, a structured reflection on the journey the mother took with her daughter and can be seen as part of her grieving process. It considers how the treatment process worked and how it could be improved for others, indeed, the mother clearly stated she felt the interview was part of her daughter's legacy.

The study further draws out the need for an holistic and sensitive approach to understanding children who have been diagnosed with cancer and the journey they and their parents are embarking on. The discussion now moves on to consider the literature in this field.

Cancer survival - Defining its medical and non-medical meanings

A commonly used clinical definition of surviving cancer is that of a person surviving the first five years following their diagnosis. In 1985, Fitzhugh Mullens, a physician, wrote a paper entitled 'Seasons of Survival: Reflections of a Physician with Cancer' where he divided survival into three seasons:

- acute survival, the period post diagnosis, when the focus is on surviving the treatment;
- extended survival, the period post treatment, when the focus is on managing, dealing and coping with both the physical and psychological results of treatment;
- permanent survival, the period when relapse appears doubtful.

Yet even in the permanent season, survivors still have to deal with the late effects of treatment which may or may not be apparent. The acronym NED (No Evidence of Disease) is used by some survivors and their family's cancer communities which describes the extended and permanent survival stages. The use of the acronym recognises the vacuum that survivors and families feel they are in, the trauma they have suffered and the fact they are still passively looking for signs of reoccurrence.

Leigh (2007) stated that "survivorship is not just about if or how long patients live, but also about how well they survive and, hopefully, thrive." 12p 10-1. Bell and Ristovski-Slijepcevic (2013) noted that when cancer is first diagnosed it is viewed as a life threatening or chronic illness, which results in a fast response to the illness and in this way it differs from other chronic illnesses which have slower response times. They highlight the fact that aside from HIV/AIDS, only cancer draws out people's fears of death. As such 'surviving cancer' or

'cancer survivorship' is open to interpretation and can mean many things to many different people and even to one person, as such, its meaning can morph even within a conversation.

The term cancer survivorship therefore has many owners, implications and connotations; it can be both subjective or objective and can be misinterpreted unless it is clearly defined by the person who is using it. This paper will use the definition of "cancer survivorship" as that created by the National Coalition for Cancer Survivorship (NCCS) as "living with, through and beyond a cancer diagnosis". This definition has been recognised by many bodies, including the American Society for Clinical Oncology.

The effects of treatment

There are widely known effects, side and late effects of cancer treatments such as hair loss, while others are less well known such as memory loss. The person may require surgery and/or may be required to be in isolation for period of time, with limited access to people and the outside world. There is a spectrum of effects and side effects which depend on treatment/s administered, these include:

1. Physical changes: for example, water balance in the body
2. Cognitive issues: e.g. memory, cognitive and organisational skills
3. Fatigue
4. Personality changes
5. Loss of fertility

:

Throughout the treatment, the family and cancer patient go through psychological trauma as can be understood by reading the work of Kissane (2011). The family is living in a complex situation, dealing with multiple and often conflicting emotions, fully aware that treatment comes with side effects which can impact on the psychological and physical state of the patient, whilst also being aware that if the treatment does not work, then death will occur.

Castellano-Tejedo PérezCampdepadrós, Capdevila and Blasco-Blasco (2016) reported positive results in relation to adolescent childhood survivors' psychosocial outcomes which appear to be linked to both personal and 'socio-family factors'. Yet, while Castellano-Tejedo PérezCampdepadrós, Capdevila and Blasco-Blasco (2016) appear to have used the medical definition of survivorship rather than the NCCS definition, as such, the question arises: What are the psychosocial outcomes of adolescents who do not reach this five-year milestone?

Treatment times for cancer vary considerably, as they are dependent on many factors including the type of cancer/s, the age and gender of the patient, the treatment type that is approved and available to the person in their country. Since 1999, the United Kingdom has had a decentralised government and more powers were given to England, Northern Ireland, Wales and Scotland, including the National Health Service. As a result, when a person is diagnosed with an illness in one country of the UK and then gets transferred to another country for treatment within the UK, the services they receive may be different from their country of origin.

Treatment is a dynamic process, the clinicians observe and react to the cancer and as such, cancer treatment is highly complex. Bleyer (2002) found that older adolescent and young adult (OAYA- 15-25 year olds) oncology patients are unique, compared to other age groups of oncology patients. They face many issues and challenges, as they are often isolated from their peers and are reliant on carers at a crucial juncture in their lives, when they are just starting to gain or strive for greater independence. This is the time when OAYAs are setting life goals and their self-image and identity is developing. They may have gone through puberty and they are starting to develop or explore closer relationships. Finally, they are reaching key points in their formal education. OAYAs therefore, face a complex set of psychological needs which, in themselves, cause emotional distress, yet when one adds the impact of being diagnosed with a chronic disease, the OAYAs' circumstances are truly unique.

Children should be included in the treatment decisions

Cancer treatment is invasive. For example, as part of the treatment process, patients may require cannulisation and/or catheterisation which can cause physical discomfort and psychological distress. Canning , Bunton and Talbot Robinson (2014) studied the emotional distress caused by cancer treatment on children between the ages of 12-18 who had been diagnosed with cancer but had not yet reached the 5-year milestone. The results showed that significant levels of emotional distress were found in both genders.

Quality of care across different locations

While many cancers have standard protocols, the quality of care a patient actually receives can vary. One of the key areas is around the communication between patient and professionals. This is reinforced by Davidson and Mills (2005), who found that it is important that the communication is personalised. Davidson (2005) further found that younger patients (those below 45 years old) were not happy with the level of privacy they received, yet it should be noted that they were an under-represented group. The report entitled 'Cancer in the UK 2014 State of the Nation Report', produced by MacMillan, a UK cancer charity, indicated that the quality of care that patients received was not of a high standard. Moreover, there were clear indications within the report that, due to the inconsistencies in the quality of care patients received, there was an identified need for improvement in patient safety, experience and reduction in costs.

Quality of life. What does it mean and how does the meaning change?

The effects on the QOL of the cancer survivor are variable and depend on the strain of cancer, the type of treatment, the differing levels of service and support a patient receives. This can vary considerably not only at a national level, but also at a hospital ward level, therefore, the quality of survivorship can be seen as being on a scale. Quality of survivorship can be measured objectively not only by oncologists, but also by other multi-disciplinary skills sets such as psychotherapists and psychologists, with each discipline measuring success according to their own scales. From the wider study that the author conducted, it was found that patients, families and the extended patients' networks create their own personal criteria for measuring the quality of life (QOL) and quality of survivorship throughout and following the cancer treatment journey. Children who have aggressive cancers go through significant suffering including fatigue, pain, dyspnoea and poor appetite. Wolfe (2000) noted that many of these issues were not dealt with effectively and the QOL of the patient deteriorated significantly.

Non-medical services and interventions

Cancer patients may not receive the same access to non-medical services, even if they are in the same ward. This can be due either to the health insurance policy in place or the service level agreements that exist when a patient is moving from one provider to another. The effects of treatment can lead to extended periods of time in isolation, for example, bone marrow transplants cause a reduction in the immune system and require several weeks of isolation and restricted access. Treatments may also cause physical changes, which may then impact on a person's self-image, emotional and psychological wellbeing. It has been recognised that children feel the need to be close to their parents in order to feel in control (Darcy, Björk Enskär and Knutsson 2014), yet they may also want to be close to friends which the ward/hospital policy may not allow. Snyder (2002) in his article 'Hope Theory: Rainbows in the Mind' discussed how the psychological state of hope affects people's ability to deal with cancer, finding that giving a person hope made a positive impact on a person's quality of life. Thus, it can be argued that while some of the side effects of cancer can be countered with medication, it is just as important to give the children hope. This can be achieved by setting goals and accessing educational, religious, counselling services or through contact with family/friends. Germann et.al (2015) further validated the strength of the hope theory for paediatric oncology patients, indicating that it helps support these children with their quality of life post diagnosis.

Methodology

The researcher used a qualitative, narrative and free associative methodological approach to data collection (Hollway and Jefferson, 2008). This qualitative approach was chosen for the study as it is well suited to investigating personal experiences that include bereavement (Goldie, 2011; Neimeyer, 2001). An advert was placed in a social media group and the participant was self-selected. All names have been changed to maintain anonymity.

The author has had multiple experiences of cancer. He has been a service deliverer, service user and educator. As a child, he lost a grandparent to cancer. As a newly qualified teacher, he worked with a child who had just lost a parent to a brain tumour. As a parent, he has a seven-year-old daughter who was diagnosed with and treated for an aggressive brain tumour at the age of two. During his daughter's treatment, he worked with a teenager who was also having treatment for cancer. As such, the author is an insider to the cancer community and it is this experience which gives him a unique perspective when undertaking research and a deep understanding of the culture and language surrounding parents of children with cancer, which is reflected in this paper. The author, like Dwyer (2009), recognises that being an insider makes them a different type of researcher and their whole life experience informs and shapes their research. The author explained his experiences to the mother and drew upon these during their conversation, identifying words, phrases, intonations or inferences that needed further investigation. There was a high level of trust given from the start by Jane, the mother, as she felt she was able to talk freely and that her family was being given complete respect. Due to this level of trust, in places the interview could be interpreted as being a focused discussion between two parents. It was also understood that the mother was participating in the research as a way of recounting the journey in order for others to learn from the experience. Therefore, the author acknowledges their position as a researcher and that they have collected, interpreted and presented data from the position of an insider, empathiser and someone who understands the narrative of the mother to a greater extent. The author further acknowledges that this creates a bias.

The research was approved by the University of East London ethics committee and participant consent was given for the use of the excerpts from her interview covering all topics, including her daughter, Susan's, feelings towards the importance of her education. It was felt that this would demonstrate the significance of education, and how it carried Susan through her cancer journey.

This case study has been selected from a range of interviews undertaken as part of a larger study examining if parents/carers feel the academic performance and social, emotional and communication skills of their children with cancer and/or those of their siblings, change as a result of the illness. This research has used use thematic analysis (Braun and Clarke, 2006). By using this approach, the thematic analysis allowed the author to recognise, examine and write the patterns that emerged from the data. While conducting the research, this case stood out due to the short period of time from diagnosis of the illness to the death of a teenage child. The interviews were conducted with the mother approximately 2 years after the child died, and ran over several weeks and many hours. The key themes to emerge from the interviews were the importance of and access to:

- close family
- her boyfriend
- religious beliefs and appropriate pastoral care
- education and educational support
- the rights of the child during treatment
- a clear understanding of the impact that cancer and its treatment has on the patient's quality of life

Data was analysed using the narrative method, as the primary method of data collection was the narrative interview (Gray, 2009). DeCinque et al (2006) used this method when researching the support that bereaved families received after the death of a child from

cancer. While this study's aims were different, it could be argued that Jane was going through a similar emotional experience. The researcher identified changes in the pace, intonation, expression and emotions and asked questions based on these. Throughout the process, Jane was asked if she was happy to continue as the issues were often sensitive. At times, the interviews evolved into a conversation and then returned to the semi-structured interview. Notes were made throughout the process and the interview was then transcribed. While writing the research, the author referred to both the transcriptions and the audio recordings.

Results

The researcher has followed a positivist positioning. The narrative presented has been constructed by the author from the various segments of data that were collected across numerous interviews with the mother.

Susan and her family: an overview

Susan was a girl in her mid-teens. She lived at home with her mother, Jane, father and two of her three siblings: Katy who was at primary school, Tom in a lower year at secondary school and her older sister, Sarah who had left home and was attending university.

Both the parents worked and there was an extended family network, but Jane did not discuss the extent of their role. Jane explained that Susan was an *“emotionally intelligent person who could and would express her feelings”* and it was evident throughout the interview that Susan had deep religious convictions and a close relationship with her mother. Indeed, it appears she was the child who had the most in common with her mother in terms of shared values and beliefs. She enjoyed supporting her peers and younger children at her school and was active in many youth groups.

Susan was initially taken to her local doctor for a minor illness, but four months later after many tests, she was diagnosed with a rare and aggressive cancer which would require a complex treatment plan. Jane received a phone call from a consultant unknown to her, who delivered the news that Susan would require a bone marrow transplant. It was also explained during this call that the transplant could not take place in Susan's own country within the UK, so she had to travel to another country within the UK in order to receive the treatment she needed. The doctor also stated 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. Jane felt that this was a harsh and clinical way to deliver the news; it left her in shock and she then had the task of breaking the news to her daughter and the family without any further facts, support or guidance. This not only included the serious nature of Susan's

illness but that the siblings would also have to undergo invasive procedures, and 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. This led to two issues: firstly, Jane felt that her youngest child, Katy, should be included in the testing, as she disagreed with the doctor's assertion that Katy was not mature enough to handle the procedure. She asked Katy if she would be tested and Katy agreed. Her son, Tom, however, was reluctant from the outset and his mother was worried that *"he was too immature to cope"*. When the results returned and Tom was shown to be a match, her fears were borne out, as he refused to be a donor. This led to a heated dispute, all of which Susan overheard, causing great distress to her and the whole family. Tom did provide the donor material for the transplant, but *'once he comprehended the serious nature of the situation and tests showed that he was a match he most definitely became a willing donor.'*

Another significant pressure on the family was the distances they needed to travel for Susan's treatment. In the first stages, they faced a three to four hour round trip to their 'local' hospital, but when it was recognised that Susan would need a bone marrow transplant which could not be done within her region, arrangements had to be made to move her to another country within the UK. This transfer presented many issues, not just around how the family would travel and live across hundreds of miles, but also around the level of service and care that Susan could and would receive. Within the UK National Health Service, different countries have different service level agreements which significantly affect the level of care that is given to patients. In Susan's case, she was entitled to medical treatment and support for education, but she was not entitled to mental health services.

During a bone marrow transplant, there is a high risk of infection, due to the immune system being severely compromised, thus, Susan was restricted to having only three family members allowed access to her. Susan asked for access to her mother, her father and her boyfriend. Her mother had to give up her job (which affected the family finances) in order to

stay with Susan during treatment. As a result, the family's routines were disrupted, but extended family and friends supported the siblings with day-to-day and weekly tasks. Susan was placed in an adult ward and Jane commented that she was "*treated and spoken to like an adult*", due to resourcing issues at the hospital. This not only caused problems with access to family and services but also placed additional emotional distress on Susan, who needed to be recognised and approached as the young person she was.

Susan's friends:

Susan had many friends and they stayed in contact with her throughout her illness. The key person who stayed with her throughout the whole journey was her boyfriend, Alan.

Susan's boyfriend:

Alan was a few years older than Susan, they had started going out many months prior to her being taken ill. Jane explained that the relationship "*was serious and they were planning on spending their lives together*". Alan was studying and so could not visit Susan in the first few weeks of her going for the transplant, so when Alan did visit, Susan's mother felt like she was receiving respite as she could leave the building. Alan would take notes and feed these back to Jane and her husband but, importantly, Jane felt he provided "moral and psychological support for Susan". Aside from Jane, Alan spent the most time with Susan. During the interview, Jane also reported that Susan had written in her diary that "*the support that she received from Alan was vital*". The family and siblings did not mind that Alan had access and spent long periods of time with her. It was also recognised that he had the psychological strength to sit with Susan.

Education:

Susan was a strong, popular student who was not only looking forward to starting the next academic year but was looking forward to her exams the following year. Jane stated that Susan "*thrived and came alive when studying and when she was told they would be moving to a different part of the UK for the bone marrow transplant, the very first thing that went into her suitcase were her school books*". Susan was in hospital when the new academic year

started and was so keen to study that she was ready and waiting for the teacher to arrive. Jane expressed frustration when she reported that Susan was “*bitterly disappointed when the teacher arrived late in the day and was even more dismayed when she realised that she would not be taught throughout the day, but only receive short sessions due to the limited service provided by the hospital*”. Such was the importance of education to her that she wanted to sit an exam but this presented another battle with the hospital, as it was an unusual occurrence. Eventually, arrangements were made for her to sit exams while she was going through treatment, but the stress of making it happen was felt by all. As a result of complications following the bone marrow transplant, Susan’s health deteriorated still further but she was keen to carry on studying. The hospital teacher not only helped Susan but also gave her mother some much needed respite, as she was unwilling to leave Susan unless she had alternative adult support. The hospital education service and Susan’s school co-ordinated her education, which ensured consistency and quality of education. As Susan became increasingly ill, she was given additional medication, which had side effects that they were not informed about. The drugs affected Susan’s ability to study, which had damaging psychological effects on her. The family was unable to access support to compensate for this loss due to inadequacies in the care agreement between the different health authorities within the UK, which did not allow for mental health services. To compound this issue, there were no third sector (charity or voluntary) groups in place to provide support.

When Susan returned home after treatment, she tried to go back to school but ill health, including the need to be on a ventilator, prevented this. The school, teachers and family friends tried to provide as much educational support as possible for Susan, and this gave her something to work towards. Jane explained that Susan was still “*determined to sit her exams after the holidays and still wanted support over the holiday period*”, at which point a local charity and friends stepped in. Shortly after this, Susan moved to an ICU unit within a hospital; she was on ventilation yet she had automatically assumed that she could sit her exams while on the ventilator. Susan’s mother passionately explained that “*the fear of not sitting her exams was devastating for her*”. She was also fearful that she would be held back

by a year and would lose contact with her peer group. When Susan found out that this was a possibility, she emailed her school tutor leader to discuss arrangements for the following year and also stated that she had accepted that it was "God's will" that she be held back a year academically. Susan died one week after this communication, ten days before the exam.

Beliefs:

Jane explained that Susan was brought up in a house where religious beliefs, practices and convictions were strong. Susan felt strongly about their faith and spoke on an almost daily basis with a minister when they were at home. The hospital Susan was moved to for her bone marrow transplant had very limited religious pastoral services. There were significant differences in the attitudes and expectations towards religious practices, leading to a big difference in service delivery. The disparity of norms between the hospital/ward and the patient/family led to confrontation between the two parties. Jane stated that the family was not given a choice over which religion they would get pastoral services from, as the hospital viewed religious support as an homogenous service, rather than recognising the differences between religious denominations and the expectations of the individuals. Furthermore, the hospital did not see pastoral services as an essential service. The family did not have access to pastoral services for over five weeks and became increasingly distressed as a consequence. Jane stated that *"Susan felt her right to religious freedom was restricted by restricting her ability to access the appropriate religious support"*. Moreover, at this point, Susan was suffering from a lack of psychological support services, the negative effects of the drugs, the stresses of not only being away from home but also living in isolation. The lack of pastoral services only served to make Susan and her family feel worse. The family discovered that the lack of pastoral support was affecting many other families, from all religions. The issue was taken up with the hospital management and subsequently addressed in favour of the families, though religious support was still not consistently provided.

Susan's Father:

Very little was said about the father's role during the interviews other than he did not work once Susan had been diagnosed and Jane explained that he found it "*very difficult to sit with Susan in the isolation room.*"

Susan's Mother:

Jane described having a very close relationship with her daughter. They seemed to share the same values, particularly from a religious perspective, which appeared to be the cornerstone of their relationship. Prior to Susan's illness, her mother had both a career and cared for the family. Therefore when Susan became ill rapidly, both Jane and the family's routines changed overnight.

Jane stated that she "*felt she had lost two children when Susan died; one through death, and another through emotional trauma*" as her son isolated himself after Susan's death and would not attend family events. During the interview, there was an audible strain in her voice at this point. Even though she wanted to discuss this issue, the pain was clearly still raw, even after several years.

Jane has gone back to work and has made a conscious effort to balance work and home life and to create routines, yet she described finding it hard to support her children while she herself is still grieving. It should be noted that while Susan was going through treatment, her mother had to deal with her own emotions and fears as well as trying to support all her other children. The strain this placed on her was very apparent throughout the interview.

The last weeks of Susan's life

In the last weeks of her life, Susan was placed in an adult ICU. The hospital did not provide the necessary social and emotional support and this caused a number of issues. Jane stated

with frustration in her voice that *“the hospital staff admitted that they did not have the experience of working with children and parents and they did not understand the needs of the family as a unit”*. For example, when treatment and care was given to Susan, such as physiotherapy or the replacement of a catheter, Jane was automatically asked to leave. While Susan received the bone marrow transplant in the adult unit, Susan was at least asked if she wanted her mother to stay during procedures such as catheterisation. Often she would want Jane there as, Jane explained, Susan would be *“fearful and distressed”*, yet in the ICU Susan was not asked if she wanted her mother to stay, which resulted not only in psychological distress, but also in physical pain as she would often tense up during procedures. Jane believed that this distress could have been reduced or stopped had she been allowed to stay. In addition, the ICU did not have the resources, facilities or inclination to allow adults to stay beyond visiting hours. It took over five days for the unit to arrange appropriate accommodation for Jane, that was close by and allowed her to wash, change and to rest. There were many more examples of the ICU staff failing to consider the psychological and emotional needs of the child and family. There did not appear to be any formal protocols for the staff to follow and they seemed unwilling or unable to be flexible in providing much needed support for Susan and her family during this time. As such, there was an inconsistency in the quality of care as different staff treated Susan in different ways. One example of this was when Susan needed to be catheterised; some nurses would ensure that there was an open dialogue to ensure as Jane said, *“the procedure was as comfortable as possible, while others would simply do the procedure without any communication, causing discomfort, distress and pain for Susan.”*

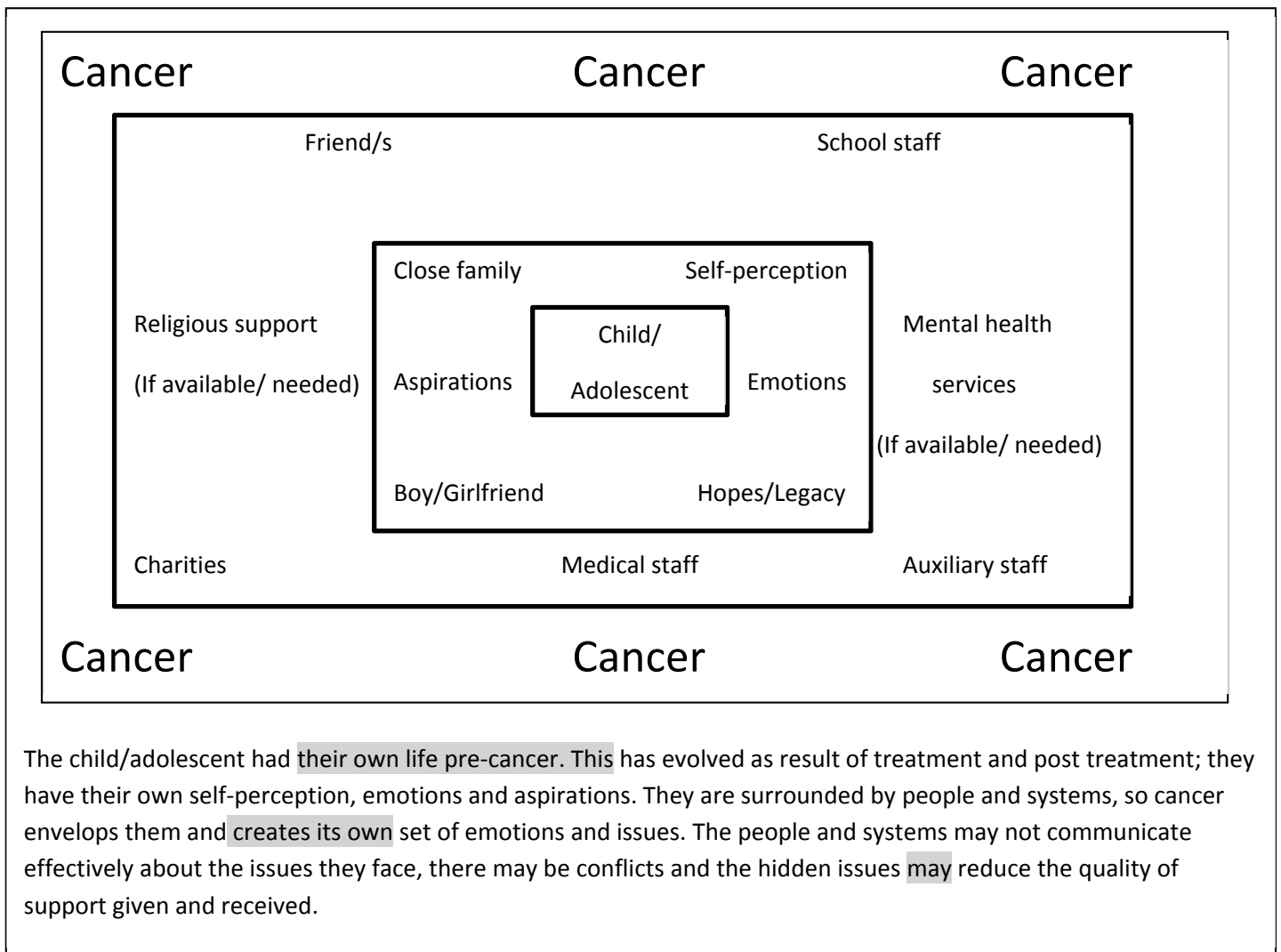
Jane met with doctors frequently to discuss her condition; these were particularly stressful occasions. She described one particular incident when she was called in for a meeting to hear that Susan’s cancer was terminal. She asked for a nurse specialist to accompany her for support and was under the impression that there would be just three people in the room: herself, the nurse specialist and the doctor. However, a new nurse, who had just started that day on the ward, was told to attend and the ward sister also came in. Jane was not

comfortable with either of these people being present to discuss a very personal issue. She was aware of them looking at her and did not feel any warmth from them, she explained:

“I felt like a laboratory rat, Exhibit A. Someone was discussing with me that my daughter was going to die and they were sitting there staring at me. I felt so stripped of my dignity.”

Jane later described how she felt and the nurse specialist responded that the issue of new people attending such meetings and where to position them is not discussed in training.

The dynamic nature of cancer: a chronic disease for a child/adolescent



The child/adolescent had their own life pre-cancer. This has evolved as result of treatment and post treatment; they have their own self-perception, emotions and aspirations. They are surrounded by people and systems, so cancer envelops them and creates its own set of emotions and issues. The people and systems may not communicate effectively about the issues they face, there may be conflicts and the hidden issues may reduce the quality of support given and received.

Conclusion/discussion

Cancer survivorship has many different meanings and the definition created by the National Coalition for Cancer Survivorship (NCCS), “living with, through and beyond a cancer diagnosis”, not only allows flexibility but it allows the child to have hope, create a legacy or work towards/achieve their dreams. In Susan's case, she was studying for her exams.

The child should be included in the treatment discussions and decisions whenever and wherever possible, even if they are a minor. It should be remembered that it is their body and their life. The child's views may change but they need to be respected and included in the process at all times. It is important to respect the child's voice and recognise their emotions and fears, and by doing this they can have a sense of control rather than perhaps feeling the victim of a chronic disease.

MacMillan demonstrated in their ‘Cancer in the UK 2014 State of the Nation Report’ that the quality of care varies not only across different large geographical locations, but as reinforced by Susan's mother, it also happens at a local level. While, without doubt, service providers have to be objective and perhaps distance themselves emotionally from the patient, they should be reflective in their practice and ensure the child has the highest quality of care available due to the nature of the disease.

The effects of treatment and the physical, psychological and emotional side effects of drugs given to the child should be made clear and explained in a way that all parties comprehend. Practitioners should review the effects of the treatment including that of mental health, both during and post treatment in order to create a balance. By regularly viewing the impacts of the treatment and drugs, it would enable the family and child to identify or better understand changes that may have occurred or are likely to occur. Effects that can impact the child's QoL and mental health can be as simple as the food they eat to the people or activities they have access to. Therefore, it is important for the child/adolescent to be able to communicate and express their feelings in a way that is safe and meaningful to them. Furthermore, access

to different modes of communication should be reviewed, as these can be vital in maintaining access to their family, boy/girlfriend, mental health, education and religious services.

Finally, every child should be allowed to achieve their true potential, even when faced with a chronic illness. I will leave the concluding words to Susan:

'I believe that I have the ability to do well in my exams but only if I get more help. I hope there is something you can do to allow me to have the opportunity to do well in my exams.'

Susan (2013) written to her education authority shortly before she passed away.

Limitations

It must be understood that the research was done in the context of a wider study, which was examining the sociological impact that cancer has on the child and their siblings as such certain questions were not asked due the ethical constraints of the research. There are many areas that need to be further researched, particularly as cancer is a global problem and while treatments are getting more effective in many areas, there are many hidden and long lasting effects which impact not just the patient but the wider family. A further limitation is that of the level of psychological distress the mother felt throughout the process of the illness crisis, during the loss and after the loss of her daughter, which could have influenced the narrative.

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