CENTRE FOR CHAPLAINCY
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RESOURCE

**Spirituality of sick adolescents
and their spiritual care needs
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MCYM Dissertation**

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Lauren Ellis
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Abstract

This dissertation looks towards the concept of spiritual care needs in young people who spend the majority of their lives in hospital. The reason for this chosen subject was as a Youth worker in a chaplaincy setting I felt that I needed to be more purposeful in addressing the spiritual care needs in the young people that I was seeing. I also wish to see this develop wider so that it is not just the chaplaincy team who are delivering spiritual care but hospital youth workers, nurses and maybe even doctors. I also wanted to go deeper in the meaning of John 10:10 'I have come that they might have life in all it's fullness.' I believe that everyone is spiritual regardless of age, gender, culture or religious belief and if this is so then the need for spiritual care within a hospital setting is one which needs to be addressed.

In this dissertation I look towards the notion of spirituality, what it means and why I believe it is important. From my research using scrap boxes I have drawn out the main themes including identity, hope and empowerment. I then go on to suggest some important aspects of being a chaplain and traits that I believe every chaplain should have.

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Chapter One:
Introduction

At the age of 18 months old I was diagnosed with a rare genetic disorder called Cystinosis. This metabolic disease means my body cannot eject one of the amino acids, cysteine, this then builds up around my body in various organs with the main area being the kidneys. It also affects other areas including, the thyroid gland, eyes, liver and heart. As the cysteine builds up it breaks down the structure of the organ and stops it working properly.

I first presented in hospital as a baby that wasn't thriving and the doctors and nurses were shocked to see I had a fractured femur and several cracked ribs. After a week of watching my parents in the ward they realised I wasn't being abused and from the tests they found that my kidney filtration system wasn't working properly. We were quickly sent down to Guys Hospital in London to see the leading consultant in the country who specialised in this rare disease.

This was the start of a long process to make me better. Over the years that followed we got to know more about the disease and the consequences if it wasn't managed with medicine and eventually a kidney transplant. Doctors started the process of looking for an organ donor for me aged 11, at this time my kidneys were working at just 9%. Fortunately my Dad was a positive match and after undergoing some intensive testing the transplant went ahead and was successful. Post transplantation I stayed in hospital for a total of 3 months. I had a great team of people around me, friends and family as well as doctors, nurses and play specialists.

As you can imagine from the age of eighteen months until my eighteenth birthday I have been in an out of hospital on a regular basis and have seen and been through many ups and down. The traumatic events my own family have been through has been mirrored many times in different faces I have seen come and go on the various wards I have been on and it is only on reflection that I can see how fortunate I have

been. Indeed one of the girls who had a transplant from her dad a week after mine died in the bed next to me. It is only on reflection that I have begun to wonder, at this point in my life, what were my spiritual needs and how were these met during my time in hospital?

For the last 8 months I have been working with the chaplaincy team at Birmingham Children's Hospital (BCH). During this time I have seen how they interact with other professionals in the NHS and the reputation they hold. I believe that this, coupled with my own experiences of hospitalisation, have led me to have an interest in spiritual needs, what they are, and how they are met during times of crisis and turmoil.

I believe that a big part of my ministry and calling is found in John 10:10: "I have come so that they might have life in all its fullness". I also believe that if we are not fully meeting these spiritual needs than we are denying young people just that. It is important that we are providing a safe place for young people to ask these spiritual questions such as "why is this happening to me?" "what does it all mean"? and "how do I make sense of everything?" (2012 UMMC)
I don't think it is necessary for us to provide all the answers but somewhere where they feel safe and find comfort and support.

During this study I will look at how well long tern, adolescent patients, ranging from 13 to 16 are being spiritually equipped to cope with the demanding pressures facing them during their stay in hospital. Nash defines Spiritual needs in Supporting Dying Children and their Families in the following way; "Spiritual Care concerns itself with the big questions of life involving who someone is, and that persons purpose, destiny, identity, potential for a relationship with the transcendent" (2011:3). With the help of this description I aim to explore the spiritual needs in adolescents in Birmingham Children's Hospital. I am interested in what they perceive these to be and how they might be articulated, understood, assessed and met. The purpose of this research is a more purposeful approach to spiritual care, not only for me, but, I hope, for others working with sick adolescents.

Chapter Two:
Literature Review

Before developing this dissertation further I must first unpack and explore a few key words. Spirituality appears to have developed more of a place in the western world in the last century. People of no faith or religious interest are beginning to recognise spirituality and its importance in their lives. Yet it is also a word that has numerous definitions according to who you are talking to.

Defining spirituality

Before exploring this research a clear definition of spirituality is needed, however, trying to find this clear definition has been somewhat difficult. It would seem that spirituality is not a word that can be put so easily into one box, but one that fits into many. Because spirituality is often linked to personal experience (Mursell 2001) it is important that various opinions are taken into account in order to paint a holistic picture of spirituality.

Spirituality finds its origins in a Christian context, however, originally there was no equivalent word in non-western languages. Spirituality is now used freely in cultures and religions which all share characteristics deemed to be life-enhancing, holistic and supportive of human well-being (King 2009)

If it is a person's job to deliver 'spiritual care' than I think it is important that a person has a clear definition of what spirituality actually is, not only in their perspective but also according to their employer; 'to avoid confusion chaplains must be clear about how they define spirituality and also about how the organization they work for understands the term' (Therelfall-Holmes, M, Newitt, M 2011:104)

I understand spirituality as something that we all have inherent within us, regardless of age, sex or culture, it is a quest to find what it is that makes us ourselves, and ties in with something deep within us that searches for more

> The theologian Bernard Lonergan (1972) suggests that…all human
> beings yearn for more. Lonergan builds his theological thinking upon
> what he calls our innate human dissatisfaction with ourselves and our
> world. For Lonergan the very process of living implies transcendence.
> (Myers, BK 1997:11)

Spirituality comes from the Latin word 'spiritus' which translates as 'breath of life', this implies that it is a crucial aspect of the way in which we live, as well as something which is inclusive to all. If this is true then I would also go so far as to say that spirituality can be separated from religion.

> A clear picture has emerged showing the spiritual awareness
> of non-church young people. They are active in making sense
> of themselves, the world and the existential questions which
> they encounter. They are recipients of the most profound
> religious experiences, comparable with any reported by the
> church attendees. Finally, they make sense of their lives
> through a faith which is constructed by centres of value and
> power, creating an ultimate environment.
> (Clapton 1993)

Swinton states that the rise of the use of the word spirituality in a western culture is forcing it to take on a new and different meaning. We must start to see spirituality separate from religion. He also sees this idea of spirituality as a way in which health care practice can become improved and more meaningful:

> In assuming that the person is in essence spiritual, irrespective
> of their involvement or otherwise in formal religion, issues of
> meaning, purpose, value, hope and love are bought to the
> fore…as such, a generic approach to spirituality has the
> potential to improve both the standard and the meaningfulness
> of our caring practices.
> (Swinton 2010:19)

Spirituality is about learning who you are in whatever situation you are in. This could be connected with a God or not, it could also be found in family or culture, as well as through nature and our environment. The definition of spirituality given by Nash in Supporting Dying Children and their families, sums spirituality up for me in its complete sense: 'A lifelong journey on which people explore their connectedness to

the world, themselves, others and possibly the transcendent, and the meaning and purpose of their lives; that which gives my life meaning and value.' (Nash 2011:3). This definition of spirituality allows room for God, if God or a God is involved in a person's life, but can also be recognisable by a non-religious person and have a deep impact on that person's life as well.

Spiritual Care

Spiritual care is for the most part, associated with religion and chaplaincy, especially within a hospital setting. However, if I am saying that spirituality can be applicable to a person of no faith then I think it is right that we look at a spiritual care apart from religion. Therefore, before we start looking at spiritual care and what it is, it is important that we look at religious care to enable us to separate the two. In his book 'Supporting dying children and their families' Paul Nash talks about religious care as being care that is provided around rituals, conversation and practices of particular faith religions (2011:2) therefore, this type of care can obviously not be done with a person of no faith. Spiritual care is defined as looking at the big questions in life, including who am I, what is my destiny and purpose etc. These are questions which, I believe, are asked of every person at some stage in their life.

I also believe that being in a position of uncertainty, such as being faced with hospitalisation or perhaps premature death, a person often wants these questions answered more quickly than would normally be required. Therefore I believe that spiritual care is no one person's responsibility, and whilst the chaplain may be called out to answer such questions, these questions can of course be explored with nurses, doctors and youth workers.

Linda Ross (1995) has an interesting view of spiritual care, and its aid in helping to achieve recovery. She suggests that spiritual care has an important part to play in health care and that it contributes towards a person's healing process: 'The level of health achieved by an individual will depend in part on the extent to which their spiritual needs are met.' (Ross 1995) If spiritual care needs are not being met fully then the NHS is failing to provide a key service which could aid healing. This is

something which Culliford would agree with. He explains that through spiritual care patients reported improved self-esteem and confidence. It made them feel that they were once more in control of their lives and improved relationships between family, friends and carers (2011:61)

I believe spiritual care has a significant role to play within a paediatric hospital setting, maybe more than in an adult hospital. Because of my experiences and knowledge of young people and listening to the questions that are asking during this stage of their lives, spiritual care is something which should be provided to all not just to those referred to a chaplain or youth worker and I believe can be provided by all: 'The provision of spiritual care by NHS staff is not yet another demand on their hard-pressed time. It is the very essence of their work, and it enables and promotes healing in the fullest sense to all parties, both giver and receiver' (Randall & Downie 1996)

'Sick Adolescents'

It may seem like an impossible task but I feel that if I am to write a dissertation on 'sick adolescents' then it is important that we define what is meant by that term. It has not been an easy task to try to find a definition as the word 'sick' now a days has bought on a completely different meaning in youth slang. I have decided that the best way in which to do this is to split the two words up in order to try to derive a definition by then putting them together.

According to the English online dictionary the word sick is defined as: 'afflicted with ill health or disease. Affected with nausea; inclined to vomit. Mentally, morally or emotionally deranged, corrupt or unsound' I am unsure as to weather I like this definition. To me it puts mental illness, a phrase which has enough stigmatism as it is, in the same box as being crazy or unsafe in some way. If a young person diagnosed with mental illness saw this definition in their ward or clinic I wonder how they would react. For me to be 'sick' means being affected with ill health that is out of your control, weather this is chronic illness or mental illness.

'Adolescent: growing to manhood or womanhood; youthful. Having the characteristics of adolescence or of an adolescent.' This definition seems to be missing something. It lacks in the emotional angst that young people display, it lacks in the element of transformation from child to adult, and all that is bought with that. I do not believe that this definition of adolescent truly encompasses all that an adolescent is.

Bailey gives an insight into adolescence that does encompass all that is missing in the above statement, she writes:

> Adolescence is a transitional stage of development between childhood and adulthood. The developmental tasks of adolescence centre on autonomy and connection with others, rebellion and the development of independence, development of identity and distinction from and continuity with others.
> (2006:208)

Adolescents are at a stage in their life where self-identity and exploration is an important issue for them. They are at a stage where they no longer want to be connected to their parents but want to be seen as people in their own rights 'their identity was initially tied up with their family, but now they are naturally breaking free from being solely associated with mum and dad' (Back, A. 2004:35) Bailey also notes the greater risk on health in adolescents as compared to those of middle childhood: 'Health needs are greater in this age band (12-19 years) than in children in middle childhood (5-12 years) or of young adults, and arises mainly out of chronic illness and mental health problems' (2006:209)

In 1968 Erik Erikson developed his stages of psychosocial development (See fig 1 below), Erikson suggested that the development of young people can consist of them passing through a series of stages, building upon each other. Erikson believed that these stages can be passed through by an individual or not and argued that failure to pass through a stage would see problems emerging in later life.

Trust Versus Mistrust	• Birth to 1 year
Autonomy Versus Shame & Doubt	• 2-3 years
Initiative Versus Guilt	• 4-5 years
Industry Versus Inferiority	• 6-11 years
Identity Versus Role Confusion	• 12-18 years
Intimacy Versus Isolation	• Young Adulthood
Generativity Versus Stagnation	• Middle Age
Integrity Versus Despair	• Old Age

Figure 1

For the purpose of this dissertation I wish to focus on stage 5, identity versus role confusion. Through this stage Erikson suggests that it is important that young people must discover their own identities including strengths, weaknesses, goals, occupations, sexual identity and gender roles.

> Drawing upon resolutions to earlier stages, one must now
> approach the task of identity formation. Erikson suggests
> fidelity is the essence of identity. To become faithful, committed
> to some ideological world view is the task at this stage; to find a
> cause worthy of one's vocational energies and reflecting one's
> basic values is the stuff of which identity cries are made. It is
> ultimately to affirm and be affirmed by a social order that
> identity aspires.
> (Kroger, J 2004:29)

It is during this stage adolescents explore different identities so to discover who they truly are. If a young person fails to complete this stage they are left with considerable role confusion. It is during this stage that young people will be in a stage of observing their life and attempting to create themselves into the person they want to be – implying a need for the space to do that. Adolescence is a tough

enough time as it is, however, an adolescent who is trying to discover all this for themselves, who then suddenly become ill due to chronic illness, cancer or through some sort of accident, then has to rediscover who they are in themselves and how their illness affects them:

> Adolescence is a difficult period in life for teenagers with no medical problems, so the physical and hormonal changes are often much more challenging for those with a chronic medical condition such as diabetes or cystic fibrosis, or those taking steroid or immunosuppression drugs. Clinic attendance can become poor or erratic; compliance with medical advice and prescribed self-care become inadequate and a source of stress between adolescent, parents and care-givers.
> (Eiser 1993)

Defining Assessment

Assessment is something that is used in health care all the time, but trying to define the word "assessment" is something that practitioners can often struggle with. George Fitchett in his book 'Assessing Spiritual Need', suggests that the word diagnosis can also be used in place of the word assessment. Diagnosis comes from a Greek word meaning 'discerning and discriminating in any field of knowledge, distinguishing one condition from another, and by derivation, resolving or deciding' (Pruyser in Fitchett 2002:16) Today the word diagnosis refers to the label or name given to a disease, especially in the medical world in which I work. I would suggest that this way of looking at assessment, in this context, is perhaps not the most helpful.

Assessment, is essentially the picking apart of data given through research! However, it has not only been difficult to actually find a definition of assessment in research but to also find one which does not use the medical language used above. The Management Research Group (MRG) defines research as a 'process that measures an individual's behaviours, motivators, attitudes or other selected qualities' it states that an assessment must be 'accurate and objective' as well as 'meet scientific criteria, as well as provide meaningful insight' (2011 MRG)

Chapter Three:
Methodology

The research will be carried out with 3 to 4 young people who already have a relationship with the chaplaincy team. Each young person will be given a small box which will contain 5-8 different activities designed to promote spirituality in young people, this includes, prayer bracelets, reflections, blob drawings etc. The box will be left with the young person so that they can do the activities at their own pace. I will also visit the young people and do at least one session with them. The box will be left with the young person for a maximum of three weeks, during this time I will make at least two visits to the young people in order to do activities and talk through the contents of the box with them.

This research project is a qualitative project in the form of case studies with young people at BCH, 'Qualitative researchers are interested in understanding how people interpret their experiences, how they construct their worlds, and what meaning they attribute to their experiences' (Merriam, S. 2009:5). For me this project is about the young people and their experiences whilst they are in hospital, therefore this research cannot be done without their input

This type of case study is that of ethnography 'an ethnography represents a detailed study of the life and activities of a group of people. It typically relies heavily on firsthand observation of their ways of acting, believing and feeling.' (Faegin, J et al 1991:4) and takes on a range of other research methods including observation and interaction,

> Another feature of qualitative research…is that it often employs several different qualitative methods. Watching people in their own territory can thus entail observing, joining in (participant observation), talking to people…and reading what they have written
> (Pope, C, Mays, N 2006:4)

My pilot study was based on a similar idea, however, instead of using a 'scrapbox' young people were asked to draw, paint or write about things that were important to them, the project was entitled 'about me'. Ideas included things such as

friends, family, religion, holidays etc. This evolved into the idea of using a box, this would mean that the young people were not restricted in how they chose to express themselves. They could do this in a range of ways including using playdough or plasticine, music cds, poetry, etc is also means that I can add things to the box in order to help the young people focus more on spirituality.

At an early age I was diagnosed with an illness that would eventually result in kidney failure, this meant that I spent a lot of my childhood and teenage years in hospital's and other medical environments. Throughout these experiences I have always turned to the church and to God and through these experiences, can now understand the importance of spirituality in such situations. Because of my experience as a long term patient I must be careful that my own feelings are not projected onto the young people who choose to participate in this work. I have a good network of people around me who I am able to talk to about issues which may occur, I must therefore be willing to talk to these people at such times.

Using visual research is a common phenomenon. In the 1970s Paulo Freire the brazilian educator asked children to collect photos in order to answer a range of questions (Thomson 2008:26) through experience Freire understood that images could play a key role in helping people to reflect on their own lives. Since this others have used visual research to empower people and to help give them a voice

> Since the 1970s…a number of adult educators, visual
> sociologists and anthropologists have placed visual methods at
> the heart of their practice in order to illuminate the familiar and
> release the voice of the previously unheard and allow different
> stories to be told.
> (Thomson 2008:26)

the use of art has also been recognised as a good tool for research and for allowing children to speak of their own experiences, '…drawings…sensitively used with

children in research, have potential for helping them to narrate aspects of their consciously lived experience as well as uncovering the unrecognized, unacknowledged or 'unsayable' stories that they hold.' (Thomson 2008:37) of course drawing is not the only legitimate form of art based research, other forms might include mapping exercises, photography, role-play and collage (Tisdall, Davis & Gallagher 2009:71)

I believe that art is an inclusive exercise and my reasoning for this is based on the fact that we are creative beings because we are made in God's image, who himself is a creative God. Therefore, my take is that everyone is creative in some way. However, this does not mean that everyone will enjoy one particular form of art, this is the reason why I have chosen to put a number of different things in the box.

It is important that all the research I decide to do with these young people is ethical, ethical research is research which is 'concerned with the need to act with due care and regard towards all those who are involved in our research, and at all stages of the research process' (Heath, S et al 2009:21) this means that my priority will be the welfare, both physical and mental, of the young people who choose to take part in my research. However, I must also make sure that my research has no loose ends and is written well, and with good knowledge; 'Unethical youth research is, by definition, research of dubious value, with question marks hanging over the credibility of its claims to knowledge.' (Heath, S et al 2009:21) As well as ensuring that my research is ethical on these grounds I also wish to carry out my research in compliance to classical medical ethics with things in mind as autonomy, beneficence, non-maleficiance, respect for persons and truthfulness and honesty. These are things that I believe I have covered, with the use of consent forms, giving the young person the choice to take part in the research and with the idea of following up a patient through the research.

One way in which I plan to conduct ethical research is through informed consent. Informed consent simply means that I, as the researcher, will make sure that the young person taking part in the research has all the information that they need about the research and what I will be asking of them; 'A responsibility on the

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sociologist to explain as fully as possible, and in terms meaningful to participants, what the research is about, who is undertaking and financing it, why it is being undertaken and how it is to be disseminated' (BSA 2002:3**)** Because I am working with vulnerable young people I have decided to write out a consent form which I will read to and explain fully to the young person before they commit to the research, I have also decided that alongside the young person's consent I will also gain parental consent. Below are a few other issues that I may need to think about in order that this research is ethically sound:

Working with children is my first and foremost issue, I will need to approach the child/young person in a way that will ensure they are comfortable and happy to cooperate with me to allow me to carry out my research.

I will also need to ensure my research does not encroach on any time that they spend with visitors or receive treatment. This will be approached by communicating effectively with the medical staff.

There is also the possibility that during the time in which I am carrying out my research the young person may be discharged from BCH. I will have to be adaptable in all situations and will make sure that the young person has some one they can give the box to if this does happen.

Analysing the data will involve qualitative analysis, using the art work that the young person has provided. Creative methods of data analysis (Tisdall et al 2009:79) often prove 'more effective for feedback and dissemination than traditional text-based outputs.' They may be easier for children and young people to engage with but it may raise problems when it comes to analysis; 'social researchers have well established techniques for analysing numbers and text, but these are not easily adapted to music, video, drama or dance' (Tisdall et al, 2009:79). I will have to be careful not to draw unrealistic conclusions from work that the young person has not intended. I will also be aware that not all young people will wish to take part in my research, therefore I will approach young people with a cautious approach and will not push anyone into doing this research.

From this research I hope to understand how young people perceive spirituality when they are in hospital and how as youth workers we might be able to address spiritual needs more competently and with more intent.

Chapter Four:
The Research

*Names of young people have been changed to protect their identity.

In this chapter I will look at my research approach, what I did and how it worked. I will also look at the analysis of the data and identify key themes that came out of the research I will then look at depth into these key themes and evaluate the research as a whole.

Young people were approached to take part in the research through referrals from other chaplains. These were young people who the chaplains had already built good relationships with. I initially approached the young people and their families through conversation and then asked if they would be interested in taking part in my research project. The project was communicated to the young people, their involvement with it, what it would entail, confidentiality etc, and the boxes were then left with them to complete in their own time. It was also explained that I would come and do some activities with them as well. In total six young people took part in the research. All completed at least one activity, either with or without help from myself, however only one young person managed to do any follow up activity.

Because the young people were mostly referred through the rest of the chaplaincy team this meant that most of the young people approached were from a Christian back ground. There was however a number of young people who I made contact with through some of the wards that I work regularly on. There was one young person in particular whom I was able to approach through the work that I do on ward 7. She was a 12 year old who was in hospital waiting to be transferred to a mental health unit, this meant that she was not feeling particularly ill but that her situation had got too bad to be at home and so the safest place for her to be was in the hospital until a place at the mental health unit became available. She was of course told that I worked with the chaplaincy team and that my research was based around spirituality, I also explained to her that I believe that everyone is spiritual regardless of background as well as the fact that she did not have to take part if she

didn't wish to. The Muslim chaplain in our team also took one of my boxes to do with a Muslim family, this was so that I not all of my research would be done with young people who were Christians.

The boxes were designed so that they could be left with the young people and completed in their own time. In the boxes were:

- Prayer beads
- A Labyrinth
- Blob feelings
- The poem footprints
- A stretchy man

Throughout my time at BCH I have had the opportunity to meet families on the oncology and teenage cancer trust (TCT) units. It was on the oncology unit that I first became aware of 'beads of courage'. These are beads given to young people and the families of young people receiving treatment for cancer. The beads are designed to provide additional treatment as well as to offer support for children and young people undergoing serious illness and treatments. Beads of courage have been recognised to have major benefits such as decreasing illness-related distress, increasing the use of positive coping strategies, helping children to find meaning in illness and restoring a sense of self in children coping with serious illness (2012 Be Child Cancer Aware) Each bead represents a different milestone in a child's or young persons treatment, for example, each time a young person finishes a programme of chemotherapy the young person is given a bead to represent that stage of their treatment. These make it easier to explain and understand treatment and have a sense of achievement when that stage of their treatment has finished. It was these beads that gave me the inspiration for developing some beads of my own. On the programme children are given beads at each step of their treatment, beads mark different events in their treatment and are different colours and textures depending on what the child has been through that day. The beads that I developed were different colours which related to feelings, the young people were then asked to make bracelets in relation to how they were feeling.

The blob series (Pip Wilson & Ian Long) are carton pictures of different scenarios, they help young people and children to identify how they are feeling in a certain situation. This was explained to the young people and they were asked which blob they most related to and why. This was followed with some discussion both about their feelings and the ward they were in and people they were with. The labyrinth and the footprints poem were printed on postcards so that the young people could write anything they wanted on the back, including prayers or thoughts.

The initial approach worked well but at times was a little tricky especially with those families that I had no previous contact with. There were also a few times when the young person was feeling particularly ill, therefore I did not want to disturb them and their families. This was the case a number of times, particularly at the start of the research, however, by becoming a little more pro active I soon found some young people willing to participate in my research.

There was also an issue with some young people about completing the box on their own. With one particular young person this was due to the fact that as a result of serious injury she had three limbs amputated and had little use of her remaining hand, therefore, the idea of having to thread beads by herself was something which she would not be able to manage. In such cases I was able to stay with the young person, to be of assistance or to simply by there talking with them whilst they completed some of the tasks in the box.

Main issues and themes that came out of my research was that of identity, hope and empowerment;

Identity

Adolescents is a time in life when Identity formation comes into play, when young people are trying to discover who they are for themselves separate from parents and what they might want to achieve in later life. With this in mind I would then ask, does an adolescent receiving treatment as an in patient in hospital have the time and space needed to properly go through the stages of identity formation?

I would like to suggest that in an environment geared more towards the care of children, this is actually very hard for an adolescent to accomplish. I fully support the emergence of specialised adolescent units such as those set up by the Teenage Cancer Trust (TCT). These wards are for the treatment of young people from the age of 12-25 suffering with cancer and are geared more towards the lives of those people, for example, meal times are less structured than that of a normal ward, this means that young people can choose what time they wish to wake up and what time they will receive breakfast, as well as some other vital things that would also help with empowerment issues. The aim of the TCT is to: 'ensure that every young person with cancer and their family receive the best possible care and professional support throughout their cancer journey' (TCT website). They do this, not only through these specialised units but with the help of specialist teenage cancer doctors, specialist nurses, youth workers and play therapists. It also becomes an environment where young people going through the same issues can support one another and build ongoing positive relationships. For me I can see a need for these types of units not only for those in treatment of cancer but for all other aspects of health care too, they support the need for empowerment, identity formation as well as maturity and the young person beginning to take control of their own treatment. I do however understand that NHS funding is at a minimum at the moment and that unfortunately these types of services for young people are not always possible.

Furthermore, adolescents is a stage where young people are discovering their identity separate from their parents. However, when a young person is diagnosed with an illness all the family want to do is to be there to comfort that young person, and whilst at first the young person may want and indeed need this, as treatment progresses the young person may feel that they want some time separate from their families, as well as families needing time separate from their child. This is indeed a healthy thing to do, especially while we are looking at identity formation but this can also be hard to communicate to one another, 'Adolescent identity formation requires an individuation process in which one differentiates self from parent without becoming totally disconnected from the family of origin' (Grotevant & Cooper 1985) sometimes another may be needed to help the young person express their wishes to family, weather this be about having more space and freedom or their agreement to medical consent. I believe that these people can and should also be the ones to help and actively encourage identity formation in young people.

I believe that to discover who you are, and all that you can be whilst in a hospital setting can be somewhat difficult. On a daily basis I meet young people who have to deal with the now very real issue of death whilst trying to form identities about who they are. In some instances a new identity is formed. I think identity is an important issue in health care and the work that we provide. I also think that we should be helping young people to develop their identity in a way that is relevant to them, and this might be different to each individual. I also feel that it is important to be reminded that whilst these young people are extremely ill they are first and foremost young people experiencing the normal in the abnormal.

Hope

Hope was something that I found to be prevalent among the majority of young people researched.

I believe that to have hope in such tough situations is something that is beneficial both to the young people and their families. I believe that hope gives young people a goal to obtain, something to aspire to and an improved future. I also believe that hope aids in the recovery process, this is something that Cressey & Winbolt-Lewis would agree with: 'without some hope in someone or something, the patient looses the will to live and may quickly fall into a state of melancholy and misery when the desire for life and living diminishes' (2000:170) I also believe that hope comes with a element of risk and vulnerability. I particularly like the definition given by Edmund et al: 'Hope is the belief, in the face of obstacles, that what we desire will be ours although we realize there is danger that our desire will not be fulfilled' (Edmund, D et al 1996:56-57) for me this definition does not look past the risk factor that hope so clearly carries. Instead it embraces that risk and gives it the attention needed. I also understand hope to be something that is found and accessed at times where there seems no or little hope, at times of suffering, adversity and misfortune (Daly et al 1999). I understand hope to be an emotion engaged with by many at times or trial and think that the majority of people would agree with me however I also understand that to see hope as an emotion is something that has been and still is disputed by some.

Hope as an Emotion.

In my research I have used prayer beads to identify emotions, however, to identify hope as an emotion is something that has been disputed throughout history. In medieval times hope was recognised as a fundamental emotion (Averill et al 1990) and something which Philosopher Ernst Bloch (1986) thought could be learned. I am not sure if hope is learned or if hope is innate. I do understand hope to be somewhat contagious, if one person has hope, and is positive and vocal in that hope, than it can encourage others to have that same hope. Hope is often likened to other overwhelming emotions such as love or anger and has many similar characteristics; all are seen as difficult to control, all are seen to alter the behaviour of a person and all are common experiences (Averill et al 1990). However, there are others who would disagree to the above comments those like Solomon (2000) who recognised hope as more of a virtue or reason than emotion.

Upon reflection, I myself wonder if hope is more of a feeling than an emotion. In Thagards book The Brain and the Meaning of Life we read 'Hope can be specific to one goal, as when you hope that you will win the lottery, or it can be more general, a feeling that at least some good things will happen to you', (2010:178) thus suggesting that hope can be seen as both feeling and emotion. In today's society however, I think that hope is more recognised as an emotion rather than a feeling, hope brings joy and happiness and a feeling that maybe things will work out for the better.

Hope is something that is seen through out many faiths, especially that of Christianity.

Hope and Christianity.

Hope is also a word that is seen a lot in the Christian faith. In the New King James Version of the Bible the word hope is mentioned no less than 129. For Christian's hope is found in the promise of Jesus, in the message that He brings and the hope that is prominently displayed through the resurrection that is celebrated on Easter Sunday.

For a hope that one day we might dwell with God in a place where there is no pain, no hurt, no fear but God's everlasting peace. This is a future hope.

Through Psalm 22 we are shown the hope that David has, this also later becomes Christ's hope at His crucifixion. While Psalm 22 starts as a Psalm of pain and lament it ends with a positive note of hopefulness, this is the Psalm that Christ remembers at his crucifixion in Matthew 27:46, as Christ remembers his Fathers faithfulness in his past He then believes that His Father must be present in this moment of agony as well (Friesen 2000:78) and although Jesus cannot feel his presence He nevertheless decides to call out to Him in his moment of pain.

I will leave this reflection with the words of Freisen when he himself tries to give a definition to hope:

> Hope is the belief that somehow God is very present in times of pain
> and will bring us through to a moment of life and resurrection. Hope
> is the ability to remember how God has been present and loving in
> the past and trust that it is also true in the present moment and will
> be true in the future.
> (2000:79)

I also wish to look at hope and faith, the contrast between them and what makes them different from each other. In 1 Corinthians 13:13 we read 'And now these three remain: faith, hope and love' this to me implies that faith and hope are different things, and if this is so, how are they different?

I understand faith to be something of which is certain, whereas hope to be something which is not necessarily certain, but certainly possible to obtain. From a Christian perspective then hope is the expectation of the things which faith has believed to have been truly promised by God. Hope awaits those things to come to fruition, it is an expectant hope, not a faint hope but one which is certain; 'faith believes that eternal life has been given to us, hope anticipates that it will some time be revealed; faith is the foundation upon which hope rests, hope nourishes and sustains faith' (Moltmann 1965:6)

Empowerment

This issue of empowerment is something that Pridmore & Pridmore discovered in their research involving the promotion of spiritual development in sick children they discovered that empowerment was important for children and young people in hospital in promoting their spiritual development and rights (2004:21-38)

As a youth worker I have learned from my first year at university that youth work is all about empowering young people. This is something that I have kept close to me through out my youth work and something that I hope I promote in all that I do. When I moved from a church setting to a hospital setting however I soon became aware of the lack of independence that young people in hospital seem to have and wonder how this impacts on their life and their general well being. It was through this research that I have experienced some very different attitudes to the words 'empowerment' and 'independence'. In conversation with one young person taking part in the research she actually laughed at the word independence stating 'nah you don't get that in here, yesterday a nurse came in and took my socks off for me!' whilst in a separate conversation with another young person she stated that she was beginning to feel more independent as 'I can do more for myself now'. It is important that we reflect on the two different scenarios that the young people were in.

The first young person Rachel* was on a unit that was supposedly meant to be for young people from the ages of 12 -16. In reality this is not always the case and children much younger than 11 are often on this ward. Rachel had her own room on the ward and her mum was staying with her.

The second young person *Laura was on the Teenage Cancer Trust unit. This meant that the unit was for young people of 12-25 years who had been diagnosed with cancer. This is often a very quite ward as there are only five bed spaces and two rooms. The nurses and doctors on this ward and trained specifically to look after and care for adolescents of this age. There is also a youth worker present on this ward.

The two girls were in very different situations and their different experiences of empowerment and independence could well be down to this. The nurses, doctors and youth worker on the TCT unit will be aware of the importance of independence to a young person and may well promote this for those young people who are well and able. Where as the staff team on the Rachel's ward may not have had this training and so are therefore unaware of this important aspect of everyday life.

For me the issue of empowerment comes out of what I see as my main mandate to the work that I am doing in the hospital that is John 10:10 'I have come that they

might have life in all it's fullness.' I can fully appreciate that for these young people life in all its fullness may be somewhat of an alien concept at this stage of their lives but surely then we should be striving to give them that full life in whatever capacity we can. I am passionate about seeing young people take control of their situations, especially those young people receiving medical care. This is largely because of reflexivity, the care that I received when I was younger changed dramatically as I moved from a protected children's hospital environment to that of adult services and I was not ready for this change. I believe that through empowerment and the promotion of independence medical staff and youth workers can work together to make this transition easier for the young people within their care.

This tie's in with the work of Friere who saw empowerment as something that comes with education. Friere sought to empower the poor in Brazil through education to better understand the world around them. I seek to educate the young people at BCH about talking to medical staff about their own care so as to know what is happening to them and their bodies, and to empower them and enable them to carry on with this practice when the young person is moved from a children's hospital to an adult environment.

The Research Approach

The first part of my research, the giving out of boxes, at first proved somewhat difficult. This was due to the nature of my placement and down to the fact that people are in hospital because they are unwell, this meant that on approaching some young people they often felt unwell and unable to do anything. These was also one occasion on approaching one young person who just seemed very upset and depressed, therefore I did not feel that it would be appropriate to ask this young person to take part in my research at this time.

Once young people were selected to take part in the research the giving out of boxes seemed easy, however, young people often did not want to be left alone with the boxes and would rather that I worked through the boxes with them. This happened on a number of occasions. Also, those young people who were happy to be left with the boxes only completed one of the activities, this was often the beads. No-one completed a prayer card and only one person completed the blob drawings.

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I also found that trying to do follow up work with young people was not achievable. This was because young people were often not in the hospital for long enough to be able to do this with and where they were they often had very busy schedules to keep to.

I think carrying out the research would have been more achievable if I had built up good relationships with a few young people before carrying out the research. This at first was my aim, however I soon realised that because the hospital moves at such a fast pace this may not be achievable. I also think that my research would have worked better if I had made more of a thing about asking the young people to put into their boxes things that were important to them, this approach worked well in my pilot study with the youth club and this may have felt more achievable for some people. I also think that I did not leave myself enough time to complete my research.

Chapter 5:
Chaplaincy Tool Kit

As a result of this research I have put together a 'tool kit' for chaplains based in a hospital setting. These are area's which I believe chaplains should be well accomplished in in order to carry out their vocation at a high level. These are areas which I have found useful myself over the past few weeks while doing this research as well as areas that I have observed in other chaplains over the last few months.

Building Purposeful Relationships

I am a very relational person and find it easy to talk to young people, families, colleagues and other professionals. Through out this last three years this has been encouraged in me and I fully understand the importance and value of building relationships with young people. I believe that when people have established a relationship with one another it is then when they are more willing to talk openly and honestly about their feelings and experiences. In the book 'Principles and Practice of Informal Education' Wolfe talks about the importance of conversation in order to help people figure out what is going on, how they feel about it and what they are going to do next: 'through conversation we turn around our ideas and experiences with each other…and we thereby also review those ideas and experiences…conversation provides us with one way in which either to revisit our experience or to entertain possibilities of future experiences' (Wolfe 2003) I believe that this is the main task of the chaplain, to build up relationships with families to support them in the difficult times and celebrate them in the happy occasions. This is something that Bull would agree with, in his research findings on The Spiritual Needs of Children with Complex Healthcare Needs in Hospital he found that relationships were of great importance to the sick child (Reynolds & Nash 2011:4) I believe that without these relationships a chaplain would find it very difficult to do their job efficiently. When I first started with the chaplaincy team at BCH I found it difficult visiting patients for 10 minutes at a time and wondered if it was better spending an hour with one family or 10 minutes with 6 families. Throughout my time at BCH I have come to the conclusion that it is better to spend an hour with one family or young person, I believe that to spend more time with an individual families shows that family that you have the time for them and that you care about what matters to them.

Accompaniers

I believe one of the main jobs of the hospital chaplain is to accompany families through different stages of their child's treatment, whether this is up until the child transitions to an adult environment or for a short while 'The role of a hospital chaplain is the task of accompanying people through times of transition' (newitt 2010:104-105) the hospital chaplain for some families may well be the only person who is consistently involved in their hospital life. Nash identifies this as journeying together (2011:42) this gives it a sense that it is less about the destination and more about the journey that is embarked on, not only by the family but also by the chaplains, doctors and nurses. This shows chaplaincy as an incarnational ministry and often a chaplain's presence in a situation can be as important, if not more, than the conversation that the chaplain offers.

Be prepared to deliver Spiritual Care.

Whilst I understand that each patient is individual and different from the next I believe that chaplains should always be ready to deliver spiritual care. I believe that to do this well with patients this should come out of relationship with them and their families and should be an ongoing process. In being a chaplain Holmes and Newitt talk about the going into a situation 'empty-handed' (2011:109) whilst I understand the importance of this I also believe that the opportunity to do spiritual care with a child or young person and their family can be often be few therefore I believe that the chaplain should go into a situation where, if needed, a spiritual care activity can be done then and there. I feel that this is something that is done well at BCH, the Chaplains have good knowledge in this area and are particularly creative at doing spiritual activities on the spot. I believe that this could be improved with the help of a spiritual resource box or a pooling together of activity ideas that can be done without or with limited resources. In his book 'Spiritual Care for Children Living in Specialized Settings' Friesen lists seven bulletpoints that he thinks are important aspects of spiritual care, they are:

- o Spiritual care must be intentional.
- o Spiritual care must be integrated.
- o Spiritual care must be inclusive.

- Spiritual care needs to be pluralistic.
- Spiritual care needs to be contextual.
- Spiritual care needs to be relational.
- Spiritual care needs to be mutual.

I think that Friesen is right in all of these points and think that chaplains should use these when they are thinking about and preparing spiritual activities to do with children, young people and families.

Chapter 6:
Conclusion

My desire to write a dissertation around the spiritual needs of sick child came from personal reflexivity, the fact that I have spent a lot of my life in and out of hospitals often receiving no spiritual guidance from the hospital chaplain or the ministry team. It also came out of a want to aid in the spiritual care of sick adolescents but with so little published literature not fully knowing what this might look like. I believe that I have a unique insight into "youth spirituality" and the research that I have carried out not only supports the view that everyone is spiritual but also cements my own thinking in this area.

It has been good for me to be able to define spirituality for myself, in the past I have often found it difficult to put a definition on the word and I now feel vindicated in my view of what spirituality is. I believe I am called to a holistic ministry, that I might show these young people what life in all its fullness could look like; I feel that I am armed with yet another tool in which to do this.

Through this research I have also learned the importance of just being with young people, showing them they are important and that they are cared for. I believe that this dissertation can have a positive influence on this area of research.

Spiritual care is an important element that is much needed in a children's hospital setting and has only recently being taken seriously within the NHS. The introduction of hospital chaplain's and Youth workers more widely is a sure indication that this is being realised. I also maintain that others in the health profession can help towards the spiritual care of their patients. Chaplain's and Youth workers could take this forward by developing training programmes for nurses, doctors and other health professionals who are interested in learning more about what it means to aid in the spiritual care of their patients.

I feel the best way for Chaplain's to interact positively with children, young people and their families and to introduce spirituality is through play and having a resources box on hand that contains a variety of activities is essential. Surprisingly, from my research, the activity that worked the best, proved to be the beads. This is something that can be done easily with young people to encourage questions about

how they are feeling, helping to build rapport and trust which could then lead into prayer both alone and maybe later together.

The blobs were a great tool when used in a one-to-one situation and had very positive results. Other activities that might be included could be clay or play dough, art materials, and poetry. All of these materials if used effectively can aid in the spiritual development of young people in hospital.

My research needs more work and further tests are needed but the results so far are encouraging and showed a positive effect on the patients and their families that took part. With a little more work these boxes could be developed as a useful tool in the everyday life of a children's hospital. Throughout my research I found many other ways in which these boxes could be used as a fundamental part of the chapel set up aiding the patients and their relatives. This dissertation has given me a new excitement for youth work and has armed me with another area in which I believe I now have the knowledge to embark on this with others.

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