NURSES’ SESSION

Cancer and the treatment: Does it make sense to patients?

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Abstract
This presentation begins to discuss the findings of an ongoing doctoral study that arose as the result of clinical experience, previous studies and ongoing reflection. Building on the work of Frankl [1] this study explores the search for meaning in the context of living with cancer. In this study people with cancer share their experience of trying to make sense of their disease and the treatments they underwent. Some of the findings that have begun to emerge include: the search for meaning is ongoing, multifaceted and may be lived out in a variety of ways, living with cancer and the treatment it demands brings many changes some of which lead to a sense of loss of control, there are a multitude of relationships involved which may help or cause distress to the person dealing with cancer, the health care team while often supportive sometimes failed to see the needs of those they cared for, while people with cancer value the expertise and knowledge of the health care team they also want the team to demonstrate compassion and sensitivity while delivering care and information, while a few people had found particular meaning to aspects of their experience all recognized that the ongoing process of searching to find meaning continues after treatment finishes. It is hoped that by listening to the experiences of these individual people living with cancer the insights gained will support the health care team in their efforts to help those undergoing treatment for cancer.

Background
Over the last seventeen years I have worked in the fields of haematology and oncology originally as a Pastoral Chaplain and more recently as a Registered Nurse, in hospice, hospital and community settings in Ireland and the UK. While being actively involved in delivering clinical care to patients and families part of my role has also lead to spending time listening to and supporting patients living with cancer. In both roles and in the different settings I have been faced with situations where people where trying to make sense of their experience of cancer, the treatments involved, the side effects and the overall effect on their lives. I was not surprised to find through an earlier study [2] that my experience was not unusual as many patients did turn to the nurses and other members of the clinical team for support in their search for meaning. From the findings in this original study and other studies [3,4] there was an acknowledgement that many of the people we support are involved in a search to find meaning but there was very little in depth knowledge of what the search entailed or how it was being acted out.

Searching for meaning
According to Frankl [1] our main concern in life is not to avoid pain or to gain pleasure but to discover a meaning in life. While an inmate of a concentration camp during the Second World War, Frankl began to question the meaning of the suffering he witnessed and experienced. While not advocating that unnecessary suffering should not be removed or relieved, he came to believe that his fellow human beings in the camp were able to endure much hardship and suffering while maintaining their humanity because they were able to find meaning to their life despite what they were going through. Building on his experience and reflection Frankl argues that it is the ongoing search for meaning in which each human being is involved that makes us distinct from the animals. Frankl continues that although much of the way we live today frustrates that search to find meaning, nevertheless the search continues [5]. In addressing one’s search each individual must also address the often forgotten spiritual dimension [5].
Searching for meaning in illness

Like Frankl, I believe that people do search for meaning at some level throughout their lives. People are continually trying to make sense of the world in which they operate. But when people are faced with difficult situations such as being diagnosed and living with cancer including the treatments it demands then that search to make sense or find meaning takes on a new emphasis. “The search for meaning is often prompted by human suffering, such as that which accompanies life-threatening or chronic debilitating illness” (Ersek & Ferrell [4] p.5) Heidegger [6] suggests that often it is only when ‘taken for granted world’ is disturbed that we begin to question the meaning of much of what we have simply accepted.

Baron [7] talks of illness not merely as a breakdown of an objective body but as a rupturing of the person’s ability to negotiate with the world. While Fife [8] claims that ‘meaning’ becomes particularly significant in the context of a serious illness because this extraordinary event imposes changes that disrupt the continuity of every day life.

The search for meaning has been described by Taylor as, “The struggling to comprehend why an event has taken place and the personal significance of that event” (Taylor [9] p.162. In the context of this research, the event is the experience of cancer and the significance of the illness to the person’s life. The search for meaning can be seen in the person whose life is changed by a diagnosis of cancer, the uncertainty it brings and the treatment it may demand. The search may be expressed in different ways but often through the unanswerable questions uttered by patients, what did I do to deserve this?”, “What is my life about?”, “Why me?” and “Who am I?” O Connor et al. [3] in discussing the search for meaning, describe it as being unique to each individual. Perhaps that is what makes it a difficult concept to define. Just as each individual is a whole made up of many often indistinguishable but related parts including the physical, emotional, social and spiritual so the search for meaning and the desire to make sense in illness is operated on and played out at many different levels.

Aims and objectives of the study

The overall aim of this study has been to invite people who have experience of cancer to speak for themselves, sharing their own experience through in-depth interviews. In keeping with the methodology chosen, that of hermeneutic phenomenology the focus was on their ‘lived experience’ [6]. The aim was not to describe a definite approach to this aspect of cancer care, nor to present a formal theory, but to allow themes to emerge that could be added to the knowledge and awareness of this issue. It was hoped that by exploring this issue at great depth that the insights gathered would add to and give greater understanding to the experience of people living with the experience of cancer.

Emerging themes

Five women and four men have been interviewed to date with diseases including, leukaemia, lymphoma, breast, testicular and ovarian cancer. While some of the participants were undergoing treatment at the time of interview others had completed their treatment, and two described themselves as being in the terminal stage of their disease, one of these participants has since died. Although these people came from different backgrounds, experienced different cancers and treatments and were treated in different settings, working with the emerging data a number of recurrent themes have begun to emerge.

The ongoing search

Each of the people interviewed recognized and valued their own search for meaning and described how it was acted out and lived out in many ways and at different levels. Sometimes the search was expressed in the form of a question uttered with no expectation of an answer such as ‘Why is this happening to me?’ Anne who was a member of a Roman Catholic religious community described struggling and questioning her faith while asking where her God was in this experience while undergoing treatment for lymphoma. While the search for meaning was connected to many different events the participants of this study also described trying to make sense of what they saw and heard on the wards as they underwent treatment, this included the death of other patients or hearing another person in pain. Sometimes the search was about making sense of day to day events. The search that each person was involved in was never complete but was ongoing and continued long after the completion of treatment. It was clear that the cancer and the treatments were not the only events these people had to deal with and so the searching to make sense was also related to these other events. Leo who had undergone treatment for acute myeloid leukaemia described trying to make sense of the death of a friend.

My best mate died . . . my best mate at that time obviously and . . . I often try to find meaning for why he died . . . because it really frustrates me, why he died . . . because that makes no sense

Each person vividly described their own experience of coming to know they had cancer and the changes it heralded. Rebecca who had undergone a stem cell transplant for acute myeloid leukaemia recalls noticing the changes in her body when she started getting
recurrent mouth ulcers and she began to ask what these changes might mean.

I hadn’t got them before (referring to the mouth ulcers she discovered), and mmm, then I found, I gradually felt quite tired and I started to, I know this is really personal but I started to worry about could it be something like HIV.

Like Rebecca each person went through a similar process of first recognizing a change in their body, something unusual such as, a bruise, feely tired, experiencing pain, breathlessness, finding a lump and then questioning what the change might mean, eventually each one of them would receive a definitive diagnosis of cancer.

Further changes

Each person also spoke about the changes and indeed the pain and discomfort that could be brought on by the treatments they had to undergo. Some spoke of the unfairness of it all and described the distressing symptoms they had experienced. For Anne the greatest distress was not being able to control her bowels when she had ‘explosive diarrhoea’ which she related to a chemotherapy agent. For Nora, a lady with breast cancer it was the feeling of sickness that followed treatment. Each person spoke of times when they felt they were not in control of what was happening to them because of these changes or simply because they did not understand what they were experiencing.

Kieran a young man who had undergone treatment for testicular cancer graphically described how he had felt completely ‘stripped’ by his experience of having cancer and the treatment he had to undergo.

Relationships

As they lived out this experience of cancer and the treatments this was acted out amidst a multitude of relationships, with their family, members of the clinical team, other patients, friends and society. Many times these relationships proved to be very supportive but there were times when those interviewed felt that people failed to understand what they were going through. Kieran did not want to be labelled or seen simply as a cancer patient because he felt people with cancer were treated differently. Richard who had received treatment for lymphoma felt that some of the doctors he had met had talked about him as if he were a piece of plumbing rather than a human being. Each person was also aware of the effect that the cancer and the treatments were having on other members of the family including parents, partners and children. Yvonne a lady with acute lymphoblastic leukaemia found it very difficult being separated from her young daughter while in hospital for treatment.

Each person also described their own ongoing relationship with the cancer they had. Leo recalled talking to the cancer and describing his leukaemia as his cells “not doing their job properly”, while Rebecca felt the cancer did not belong to her and refused to use the term “my cancer”. Nora hated her cancer and felt it was eating away at her body and Anne described her body as being in disorder.

Appropriate care

Amidst these relationships the participants described appropriate and inappropriate care given by family, friends, and health care professionals. When Anne was asked to describe a difficult time in her treatment she recalled an event when all she wanted from a nurse was her to acknowledge her presence.

The nurse who wouldn’t look at me when I was really ill, she was an agency nurse, now that was very hard … because that was at a time when I felt like a leper, sort of thing, a thing cast out, you know … and needed … to know it was alright to be me … even as I was, when I was really ill (Anne)

Unfortunately this particular nurse had failed to fulfil this simple caring act. Although each person used different words and different expressions what these people appeared to want most from health care professionals was their expertise and knowledge but with a caring manner, to be treated as human beings. Nora described one doctor as “heartless” because of the abrupt way he had given her bad news, but Nora was also able to describe another doctor who had supported her throughout her treatment and who also had to break bad news but who had done it with sensitivity and always treated her as a “friend”. Robert liked the fact that nurses and doctors remembered his name and took the time to explain things to him. Yvonne felt that sometimes all she and others needed was to be held in a caring manner.

A common bond

In meeting with other people who had cancer, on the ward, while waiting for an appointment in the outpatients department or in their own neighbourhood the people in this study valued the support they were able to give and receive through their shared experience with others. They were able to laugh together, share helpful ideas while recognizing the similar discomforts and difficulties they had endured. Most of those interviewed would movingly recall some of these people whom they had shared time with who had since died.
Finding meaning

While all of the participants described the search as continuing and constantly changing some of those interviewed felt that they had come to find some meaning. Nora believed that her cancer was directly linked to her own inability to deal with stress and anger, while Robert felt his cancer might have been related to the work and lifestyle he lived. Anne had found a new and deeper meaning to her Christian faith and felt she was now able to help others through difficult times. All of the participants had come to discover new meaning in their relationships with friends and family and had a greater appreciation for those who cared for them. Rebecca had made some positive changes to her working environment and valued the simple act of having a cup of tea with a friend. Each person had looked again at what was of real value to them and had made changes in the light of this reflection.

Conclusion

The field of haematology and oncology is an exciting world to work in as we see medical and supportive care advances bring real hope to people living with malignant disease. Alongside these advances people with cancer and indeed their families and friends continue to try and make sense of the experiences and treatments they are going through. As we continue to work in busy and demanding environments with increasing workloads and pressures we may not always see or respond to this aspect of the cancer experience. By exploring the findings in this ongoing study and by reflecting on their meaning it is hoped that they will help us as practitioners to address this sometimes neglected, often misunderstood but vital aspect of cancer care. In her writings Verena Tschudin [10] rightly states that in order to carry out the role of nurse, doctor, priest, parent or friend to another, we first need to be these things to ourselves. In order to support another person in their own ongoing search to make sense of their experience we need to be aware of our own search to make sense of life events and encounters including those we witness in our clinical practice. The search to find meaning and to make sense as described by the people in this study is but a glimpse of the ongoing search that each one of us is involved in. As nurses, doctors and patients in our common bond of humanity by listening to the experiences of people who have experienced cancer we can reflect on our own experience, be sensitive to our own needs and respond to the needs of those trying to make sense of cancer and the treatment journey.

References