

From nurse to service-user: a personal cancer narrative:

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There is no conflict of interest.

ABSTRACT

This article presents a 'snapshot' of my experience of being a nurse who became a service-user with breast cancer. It begins by outlining the Humanisation of Healthcare Framework (Todres *et al*, 2009), which is a values-based context which can be used to underpin daily care. Generic suggested applications for each of the dimensions of the framework are provided. This framework is then used to contextualise my experience of receiving my diagnosis and the ensuing chemotherapy. Using the examples I present from my personal narrative, I make some recommendations for "small actions" that can contribute to more humanised and person-centred care. I also hope that this narrative prompts reflection by the reader and thus enhances the quality of care given to others.

KEY PHRASES

1. A narrative of the impact of being a nurse and becoming a service-user, with breast cancer.
2. Presentation of suggested application of the Humanization of Healthcare Framework (Todres *et al*, 2009).
3. Focus on the specific themes of diagnosis and chemotherapy treatment.
4. Selected recommendations are included for future practice for oncology nurses and students.

KEY WORDS

humanising care, oncology nursing, narrative, service-user, breast cancer

INTRODUCTION

This article is a narrative of some of my experiences as a nurse, who became a service-user with breast cancer. I seek to present my perception of this, interplayed with the Humanization of Healthcare Framework (Todres *et al*, 2009). By doing this, I am expressing my service-user and professional voices to stimulate both nursing students and qualified nurses, within oncology nursing, to pause and reflect on their own practice. I will explain the Humanization of Healthcare Framework and use selected dimensions to discuss aspects of my cancer journey, specifically focusing on diagnosis and chemotherapy. I conclude by making some personal recommendations for “small actions” which can humanise care, based on my reflection on my experience.

As a nurse for 35 years who has held a variety of roles, I am very conscious that the service-user is at the centre of the care we all provide and that every service-user is unique. The service-user’s voice is ever-present within health and social care settings (Morrow *et al*, 2011) and narratives themselves are taking a more prominent place in informing care (Charon, 2008). Narratives are now presented in a range of accessible formats such as Victoria Derbyshire’s (2015) blogs about her breast cancer journey and Gloria Hunniford’s (2006) book about her daughter, Caron’s, battle with breast cancer. These narratives seek to humanise care by developing the understanding of an individual’s lived experience.

For the purposes of this article I have chosen to refer to myself as a service-user. However, I acknowledge many other terms are interchangeable with this (for example; patient, person affected by cancer or client) and are therefore substitutable.

WHAT IS THE HUMANIZATION OF HEALTHCARE FRAMEWORK?

Todres *et al* (2009) developed their Humanization of Healthcare Framework and it provides a value-based context for holistic person-centred care, embedded in what it is to be ‘human’.

It is not 'per se' a didactic model for caring, more a framework that provides a structured understanding of the values that underpin day-to-day care and acknowledges that every person is an individual with individual needs. The framework comprises of eight dimensions (values) of humanising care with the antithesis, the dehumanisation of care. This is presented in Table 1, together with my suggested applications for each of the humanising/dehumanising dimensions.

Forms of humanisation	Suggested application	Forms of dehumanisation	Suggested application
Insiderness	The subjective view of the person themselves	Objectification	Being treated as a commodity
Agency	Total responsibility for oneself, including choices and actions	Passivity	Being submissive and yielding to the will of others
Uniqueness	Being the one and only	Homogenization	Being one of the crowd
Togetherness	Being connected with others	Isolation	Social separation
Sense-making	Awareness and understanding of situations	Loss of meaning	Loss of awareness and understanding of situations
Personal journey	Personal desires, hopes and ambitions	Loss of personal journey	Loss of personal desires, hopes and ambitions
Sense of place	Place or state of safety	Dislocation	Loss of place or state of safety
Embodiment	Unification of the mind, body and spirit	Reductionist body	Separation of the mind, body and spirit.

Table 1: Adapted from the Humanisation of Healthcare Framework (Todres *et al*, 2009, p. 70)

Using Todres *et al*'s (2009) framework and my application of it, I seek to provide some personal illustrations from my experience of receiving my diagnosis of breast cancer and chemotherapy treatment.

THE LIFE CHANGER: DIAGNOSIS

Following a routine mammogram and subsequent follow-up at the local Breast Screening Unit, a lump in my right breast was noted and a further mammogram and ultrasound revealed fibrous tissue; I was given the all clear. For the next few months I kept my 'eye' on the lump but thought it could not be serious as I had been given the 'all clear'. Seven months later, I was concerned as the lump was bigger. I contacted my General Practitioner who reassured me that there could not be anything abnormal as nothing had shown earlier in the year. I persevered and had a chest X-ray and routine blood tests which showed no abnormalities. A further ultrasound was requested. By this time I was certain I had breast cancer; no-one else was. At the ultrasound the consultant said that he needed to refer me to colleagues. Within three days I had an appointment at the Breast Clinic. A further physical assessment and mammogram followed, together with an ultrasound and biopsies. I overheard a whispered conversation in the corridor saying "She didn't bring anyone with her". I knew for certain, I was now a service-user with a critical illness.

On being told my diagnosis, within minutes I began to feel governed by my breast alone and who I was had disappeared (a unique individual who had recently moved, a mother, a grandmother and someone excited about starting a new job), an example of objectification (Todres *et al*, 2009). A further objectifying experience occurred when I had my Computed Tomography (CT) scan to see if there were any metastasis. This was terrifying because, as a nurse, I knew why they were doing the scan even though no-one informed me directly of this. When I was lying down preparing for the scan, the two imaging department staff talked over me rather than to me. At the time I wondered if this because they were aware I was a nurse or whether this was how everyone was treated and I was just a 'task' to be done.

The days waiting for the results were harrowing for myself, as at this stage I had chosen to protect my family until I had all the information and I felt very isolated (Todres *et al*, 2009). Finally the appointment with the surgeon came. My world and personal journey (Todres *et*

al, 2009) stopped abruptly; every aspect of my life needed to be re-evaluated. I was now a statistic on the Cancer Registry, the “unlucky 1 in 8”; those powerful spoken words that will resonate in my ears forever.

Two days later I attended the oncology clinic with my family and was told the diagnosis and treatment plan. This was done in a very person-centred way by acknowledging that I was a nurse whilst understanding that my family were non-medical. Even as a health professional, my mind was in disarray as I could only see uncertainty on hearing the words that informed me of my diagnosis – two Stage 3 Ductal Carcinomas. The treatment plan was explained: six cycles of chemotherapy followed by surgery (unknown at this stage – possibility of lumpectomies or mastectomy and lymph node removal) and then 3-4 weeks of radiotherapy. My loss of personal journey (*Todres et al, 2009*) was immense and immediate and my thoughts were racing. What about my new job? Would I see my grandchildren grow-up and married? Would I be a great-grandmother? In amongst the sense of objectification that I now felt, I had the sense of loss and homogenisation (*Todres et al, 2009*). Nevertheless, there were small, but very important actions, which made me feel human and valued, namely, staff using my name and ensuring they pronounced it correctly and hugs of support from the breast care nurses which I saw as caring behaviours (Department of Health and NHS Commissioning Board 2012; *Zamanzadeh et al, 2010*). This, combined with the support of my family and friends, provided me with moments of a sense of uniqueness and togetherness (*Todres et al, 2009*). .

THE LIVED EXPERIENCE OF CHEMOTHERAPY

Choosing chemotherapy?

At the appointment regarding informed consent for chemotherapy I was confronted with a simple choice, to have the treatment or not. From an individual with a strong sense of agency, I found myself passive (*Todres et al, 2009*). There is no real choice in this situation

as the options are, do I choose to live or do I choose to die? There is no choice either in the chemotherapy regime (six cycles every three weeks of FEC-T (Fluorouracil, Epirubicin, Cyclophosphamide [FEC] and Docetaxel [T]), nor when it would start (three days' time). Again, the sense of loss of personal journey was immeasurable (Todres et al, 2009). I felt I was on a conveyor belt of treatment that led directly to a rollercoaster, knowing I could not get off. My life for the foreseeable future was to be dictated by hospital appointments, treatment and side-effects. I felt I was a hamster on a medical hamster wheel, feeling disempowered which was a totally alien experience both professionally and personally as I lost my sense of uniqueness and embodiment (Todres *et al*, 2009).

What made a difference to my situation were the small actions; being in a private room for the discussion, being treated as a professional person with knowledge as well as a service-user by a nurse who actively listened to myself and my daughter as we faced the unknown world of treatment and the unanswerable question - would it work? However, I did feel deluged with so much literature that I was given to take home from this, and previous appointments, and I found this disempowering when the intention was the opposite.

The fear: first treatment

The apprehension building up to attending the oncology suite for the first treatment on a Friday afternoon was almost unbearable. I wanted to run and hide. I was so emotional as I had just left my previous job and was now unable to start my new job and my daughter was now my carer. This was a total role reversal and so hard to adapt to as my role was (and is) to protect and care for her. I no longer felt I had my professional identity as a nurse and I was no longer a mother to my two children; my world had lost its meaning (Todres *et al*, 2009). As soon as I sat in the chair, I started to cry. I felt so vulnerable and isolated as no-one else can undergo the treatment for you and no-one can say how it will affect you, they can only walk alongside with kindness and understanding (Campbell, 1984, Gilbert, 2013). The oncology nurses demonstrated their compassion and caring by taking me to a private

room, making me a cup of tea, giving me a hug and finally saying I could wait until Monday to start the treatment. I felt empowered and a sense of agency (Todres *et al*, 2009), albeit only for a moment. I decided to continue with the treatment that day. On reflection, a holistic needs assessment to inform my care would have been beneficial as through this I would have been able to talk about what mattered to me before commencing chemotherapy.

The oncology nurse that stands out to me the most in my visits was genuinely interested in me and my life outside the oncology suite and this not only helped me to feel relaxed, secure and unique (Williams and Irurita, 2004), but also provided me with a feeling of insidership (Todres *et al*, 2009). She remembered my name each time she saw me. She demonstrated her knowledge and competency whilst being gentle during the giving of the infusions and explaining the medication for the next 20 days of self-care. Those 20 days are when, for me, the feeling of isolation and dislocation were at their most powerful (Todres *et al*, 2009).

Home alone: self-care

I kept a daily diary of my side-effects to take to each pre-chemotherapy appointment. From the night of the first dose, I had tinnitus and nausea. My lowest point was one particular night when I felt I was going to die. This was after my first treatment of 'T' which was the fourth dose of chemotherapy. I developed insomnia and by day five, I had started being sick and diarrhoea took hold, so my personal, and extensive pharmacy was invaluable as was my nursing knowledge of what to take for which side effect and when. Each cycle, I had developed leg pain and excruciating lower back pain due to the G-CSF (granulocyte-colony stimulating factor) and the fatigue was increasing. Fatigue is a phenomenon that I underestimated as a professional; such a simple word that undervalues the impact it has on every aspect of what you try to do daily. My mouth was sore and I had no taste, I had several nose bleeds and, for me, my temperature was raised but had not reached 38 degrees centigrade when it is an oncological emergency. I felt like a "chemical toilet".

I was alone at home on the night of day ten of this cycle of treatment. At this moment, I thought I was going to die but what remained of my professional 'head' tried to tell me that I would not. The pain, sickness and diarrhoea were unbearable. I felt unable to call 111 because the doctor-on-call would ring back and I might not have been able to answer the call whilst dealing with the side effects. I knew I needed help and support, so I decided to ring the oncology emergency number in the early hours of the morning.

As I sought to explain my symptoms and concerns to the nurse at the other end of the phone responded by saying "Take some Oramorph", to which I replied I did not have any. She told me there was no-one there to write it up and to use a heat pad and phone back later if I needed to. I was at the end of my tether physically and emotionally, scared and alone and I felt I had not been heard. I came off the phone feeling more isolated and that I had been an inconvenience; I felt objectified and homogenised (Todres *et al*, 2009). I was passive (Todres *et al*, 2009) and this led to an increase in my sense of vulnerability and fragility. Furthermore, my home was no longer a safe place, my sanctuary from the world where I could relax. I felt isolated and dislocated (Todres *et al*, 2009) and unable to self-advocate and be assertive. Home was a place where I feared dying and my body was under attack, both from chemotherapy and cancer. On reflection, I would have appreciated an individualised response which would have reassured me that I was cared about, whilst giving me a sense of insidership and uniqueness (Todres *et al*, 2009); for example, asking me if there was someone with me or was I able to phone an on-call doctor for Oramorph?

SUMMARY AND RECOMMENDATIONS

Within the restriction of an article such as this, I can only provide a snapshot of my cancer journey and it is a personal narrative. I have sought not only to describe the Humanisation of Healthcare Framework from my own understanding, but also apply it to my experience

thereby illustrating some of the dimensions. I hope this will stimulate your personal reflection.

As I have experienced, 'small actions' can make the difference between humanising and dehumanising the care we give. My recommendations include, avoiding corridor conversations about a service-user when they are in earshot and talking over the service-user when they are present which helps reduce objectification. It is also important to note, that at a time of vulnerability, words are powerful and will remain with that person forever. Keep in mind when answering the telephone that this also should include a holistic approach – the person at home may be scared, alone and isolated and feel further isolation after you hang up. Recognising the service-user when you see them more than once, together with checking you are pronouncing their name correctly demonstrates caring behaviour and bestows a sense of uniqueness. Finally, providing a sense of genuine interest in their individual lives, outside of the chemotherapy suite, also contributes to the sense of uniqueness and togetherness at this challenging personal time (Todres *et al*, 2009).

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