

## “Time for a Promotion? No, It’s Not for Me...” How Caring for Children with Life-Limiting Conditions Affects Health Care Assistants’ Career Decisions

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### **ABSTRACT**

This paper discusses the relationship between the level and experience of care provided by Health Care Assistants (HCAs) to children in palliative care and the HCAs’ views about their career progression. An ethnographic approach was taken to explore the reasoning that informs Health Care Assistants’ choices about whether to pursue a career pathway into nursing. The author, a medical student, conducted the study using participant observation while working as a volunteer for one year in a Children’s Hospice in England. The data presented and analysed here were collected through unstructured conversations with the HCAs. It was found that the main reason why HCAs declined opportunities to progress in their career to nursing was their fear of not being able to be emotionally available to the children with whom they worked. HCAs also wanted to avoid working in hospital settings, where they perceived that they would have to trade off emotional involvement in caring for patients against career advancement. The decision to pass up a promotion, in some cases several times, is not easy, especially when pay may be substantially higher. This study shows that participants’ job satisfaction and valuing of having time to provide compassionate care were the main motivations to avoid progressing from HCA to nursing roles.

hierarchies, moral codes and norms about conduct and behaviour. Hochschild (2012), Lutz and Abu-Lughod (1990) and Rosaldo (1984) encourage us to consider emotions as central to understanding social contexts and human experience. Because emotions are socially constructed, they provide refractive potential for understanding social and cultural orders.

Healthcare settings have proved to be particularly rich environments for the exploration of emotions. Emotions are strongly invoked during patients' experiences of health and illness throughout their management and treatment, often even beyond hospital discharge. Thus, the concepts of care and caring have unsurprisingly become important in health research (Mann 2005). Studies of the emotional labour involved in caregiving by nurses in the Global Northwest have shown, consistently, that caring as an emotional activity is important to nurses in terms of their personal and workplace identity, connectedness and responsiveness to patients (Henderson 2001). However, Henderson (2001) also found that nursing staff perceive that the emotional labour involved in care-giving is neither institutionally recognised nor valued, and may even be denigrated by other healthcare professionals, while at the same time, the professional clinical role expected of nurses can diminish their ability to perform the emotional work they define as care. This resonates with the earlier work of Staden (1998), who found that nursing staff defined caring in terms of attentiveness to others by giving time and empathy, and felt that these skills were not taught but acquired experientially, and were not institutionally recognised. Interestingly, Hochschild's research in healthcare settings led her to develop the concept of attunement – which invokes emotional connectedness, responsiveness to patients and alignment of care needs and care-giving – as critical to experiences of emotional labour in care-giving and what she terms “appreciative starvation”: the perception that the emotional aspects of care-giving are under-rewarded economically and at risk of marginalisation because of pressures on nurses to work more quickly and dedicate less time to individual patients (Hochschild 2003, 69).

It is now well understood that a consideration of emotions in everyday life enriches our capacity to understand social interactions, the cultural and relational factors that influence and regulate behaviour, and the ways that social structures impact feeling (Williams and Bendelow 1995). Moreover, studying the role of emotions in society and culture can help illuminate how social fields such as gender, work, and family are constituted, experienced and enacted (Williams and Bendelow 1995).

The use and experience of emotion in the world of work has been a fecund research area for social scientists, especially Arlie Hochschild (2012), who has deepened our theoretical understanding of how work invokes and demands emotional labour, which is often unrewarded. Central to Hochschild's thesis is that emotional labour is an acquired skill that requires people to learn and demonstrate appropriate ways of feeling, expressing their own emotions and responding to emotions of others. Furthermore, emotional labour both makes and partakes in the social, cultural and relational contexts in which it occurs. This insight rejects conceptualizing emotions as innate universal experiences and expressions of feeling, proposing instead that they can only be understood in specific socio-cultural settings.

This sociologically inflected approach to emotion aligns very well with the work of anthropologists (for example, Rosaldo 1984; Lutz and Abu-Lughod 1990) who explore emotions in the everyday life of small, relatively closed communities outside the global north. Their research has shown that emotions are central features of ‘little cultural worlds’ where what is possible to feel, by whom and in what contexts are framed by local modes of language and discourse, relationships and social

The views and experiences of emotional labour amongst Health Care Assistants remain largely unexamined in the research literature. This study sets out to explore the experience of caring amongst HCAs working in a charitable healthcare setting that provides nursing and palliative care to children with life-limiting illnesses. It demonstrates that particular forms of emotional attunement are central to HCAs' professional identities and represent a central element of what they identify as their workplace labour. They perceive a tension in their potential for career progression, usually into nursing, due to the threat posed to their capacity to engage in that form of labour.

## **Palliative care for children and young people in the United Kingdom**

There are approximately 23,500 children and young people in the UK diagnosed with life-limiting or life-threatening illnesses. About half of these children will have substantial palliative care needs, with around 3,000 deaths each year. On average, 100,000 family members each year will be affected and in need of support.

Life-limiting illnesses are described by the charity Together for Short Lives (2016) as those resulting from health conditions with no hope of cure and from which patients will die. Life-threatening illnesses are those health conditions in which treatment is possible, but may not be successful. Children's palliative care is an active and total approach to caring for children with incurable diseases from point of diagnosis, throughout the child's life, death and beyond for family members if needed. This type of care encompasses biological, physical, psychological, emotional, social and spiritual elements, focusing on enhancing quality of life for the child and providing ample support for the family (NICE 2011).

### **The Children's Hospice**

The setting for this study was a children's hospice in the northeast of England providing care to children aged between zero and six years old who suffer from life-limiting or life-threatening conditions. Beyond this age, the children are passed over into the care of another hospice in the local area, should their

healthcare plan allow it. The hospice was formed through a pro-life charity [anonymised] in response to the Abortion Act 1967. The charity set out to support 'total pro-life action' in response to the prospect of abortion due to disability, which the charity considered an act of discrimination.

The hospice works in partnership with complex care teams within the National Health Service (NHS), a government funded public service, to ensure consistent holistic care is given to each child. This can include physiotherapy, nursing care, medical care, pharmacology, music therapy, sensory room activities and stimulation, speech and language therapy, parent or sibling groups, counselling services, hydrotherapy, complementary therapy and bereavement support. The hospice has recently implemented a partnership with a local family medicine clinic (known as General Practice (GP) surgery in the UK), responsible for the treatment of common conditions and a point of referral to specialists in other circumstances. Currently, the hospice works with three physicians who are called when a child's health deviates from norm but not seriously enough to require ambulance services. This service provides ongoing care from physicians who have prior knowledge of the children and their individual care needs – the kind of knowledge that can prove critical in emergency situations. Furthermore, the hospice can now legally provide end-of-life care in partnership with the local hospital, which requires collaboration with a palliative care consultant.

### **Staffing and clients**

The hospice can accommodate six children at any one time with 30 children currently utilising the service. Children are invited to stay as the family's schedule and financial circumstances permit. Each child is cared for by a HCA, although it may not be the same HCA on each visit, to allow all healthcare professionals to get to know every child's individual needs in case of staff absence. To support the HCAs, at least two nurses are present each shift to administer medicine, take charge in emergencies, and complete legal paperwork. Twenty HCAs and fifteen nurses are currently employed by the hospice. Three of the nurses

are outsourced 'bank' nurses, which means they are principally employed by the local hospital, but can choose to work at the hospice when their hospital schedule allows and the hospice is understaffed. The national hourly pay is £7.33 for a HCA and £13.32 - 23.31 for a nurse.

There are two managers, one responsible for the healthcare team and another responsible for the administrative team, who both report to the board of six volunteer trustees. In addition, there are domestic staff who maintain the hospice and five fundraisers who work hard to collect donations to sustain the charity's £1,200,000 yearly budget.

### Role of Health Care Assistants

The following extract from my field notes on my first visit to the hospice serves as a reflective introduction to this article:

All HCAs have their designated child and are playing with them whilst the nurses fill out any related paperwork, prepare medications and talk to management about children coming in the following day and sorting out shifts.

All care is provided on a one-to-one basis by a specially trained HCA who works under the guidance of a nurse. The HCAs' responsibilities include washing and dressing the children, helping with feeds, helping the children move around, or playing with them – especially using stimulating sensory toys – alongside monitoring patients' conditions by taking temperatures, pulse, respirations and weight. During the day, the HCAs take pictures and make detailed notes of the children's activities in a "My Day at [hospice name]" worksheet, which will be kept in a 'Memory Box' dedicated to each individual child that will be given to the child's family as a gesture of support when the child leaves the hospice or passes away. The HCAs are usually the ones who greet parents upon arrival and tell them how well the child has been during his or her visit when parents come to collect them.

### Role of Nurses

The children have very specific health needs and their families are viewed as partners in the care offered so each child is assigned to a Registered Children's Nurse who updates the child's care plan monthly, incorporating

caregivers' requests where appropriate. This reflects the organisation's belief that every child is unique and that each care plan should be tailored to the needs of the child. If any problems arise during the child's stay, a nurse must call the parents. There are always at least two nurses on shift, as well as one care assistant per child. This level of hands-on support ensures that all children receive the attention and care that their conditions require. All members of the management team have a background in care work themselves, which fosters a better understanding of what the children and staff need.

### Methods

I collected data for this paper alongside an assignment set by the university at which I am studying medicine, which requires all medical students to take a year-long placement in the local community. The purpose of the placement is to help medical students acquire a broader socio-cultural understanding and experience of health and illness. By placing students in healthcare environments outside the formal, government-funded health system, the community placement also enables students to see how the wider informal healthcare system operates. Students are required to submit an assessed report on our experiences that takes the form of an ethnographic project. This approach encourages the development of qualitative research practice as well as a formal intellectual foundation for understanding what health means and how it is experienced by members of the local community.

Ethnographic studies seek to provide a comprehensive understanding not only into the actions of an individual, team, or organization, but also into the interactions and perceptions intertwined with them. To obtain a more holistic view and to try and enrich my understanding, I used several research methods, combining information from various sources in order to achieve data triangulation. The methods were participant observation, informal unstructured and semi-structured interviews, analysis of textual data and questionnaires. Confidentiality, anonymity and the right to withdraw were explained to all participants prior to their involvement, and questioning only began once consent had been

given. In this article, pseudonyms are used for participants to preserve their rights to confidentiality and anonymity.

*Participant observation* allowed me to immerse myself in various ongoing activities at the hospice which, as an investigator, gave me the opportunity to interact with other people in events and situations as they developed. It enabled me to understand an experience from the point of view of a participant, as opposed to a mere observer (Shaw 2016). However, one limitation is the 'Hawthorne effect', which describes a behaviour-modifying reaction by an individual in response to their awareness of being observed (McCambridge et al 2014). Thus, my presence as a researcher could have potentially influenced situations. To mitigate this, I only wrote up fieldnotes after I left the hospice, to try to prevent individuals from feeling they were under surveillance. This delay, however, could have resulted in recall bias. However, it has been argued that establishing a close relationship with participants can "reveal profound truths about social and/or cultural phenomena...even if staged for or influenced by the observer" (Monahan and Fisher 2010). I found this to be very true – when comparing responses obtained from interviews and those from questionnaires, the questionnaire responses were very brief, with no rich data.

In-depth *unstructured and semi-structured interviews* conducted with staff, especially after establishing rapport, enabled the collection of much more detailed data. These explored the thoughts and emotions experienced by staff who were involved in the clinical, operational and financial aspects of palliative care at the hospice. I also interviewed parents and siblings to enrich the data collected and provide users' perspectives on the organisation. Unfortunately, due to their health conditions, the children themselves are unable to communicate. Questionnaires were utilised as a research method after a considerable number of hours had been spent on placement, allowing more time to become familiar with the staff and parents. This increased the likelihood of obtaining engagement with, and understanding of, and therefore confidence in the survey. The main purpose of the survey was to cross-reference and supplement the data collected from the hospice staff by other

means. For example, there was no private space to conduct interviews so interviewees could easily be overheard by other staff members. By using a self-reported paper questionnaire, I was able to gain more private answers to certain questions. I included both open and closed questions to easily compare responses with interview data and strengthen the reliability of findings.

Shaw (2016) states that the potential ways in which the researcher's involvement influences research should be monitored through *reflexivity*. After writing fieldnotes, I reflected upon that period of fieldwork, identifying areas where it was possible that perceptions of my role or interest were influencing either what I saw or heard or my interpretation of it. It has been shown that continual reflection can have a positive impact on a researcher's approach to their study (Claxton-Oldfield and Claxton-Oldfield 2012).

## Findings: The Rewards of Emotional Labour

It is well-documented that in nursing, as in any occupation, employee satisfaction depends heavily on the opportunities for career progression (Hayes et al. 2006). In the hospice, the management team encourages career development from HCA to nursing status because nurses can be more involved in the clinical care of the children. There is a need for more nurses on the staff rota, which is why the hospice has to resort to the bank nurses. To support progression from HCA to nursing, the hospice allows for a fully flexible work schedule to incorporate study leave, and some financial help is available. For this reason, it was surprising to see that many HCAs had no interest in this career progression.

In order to understand the decision to pursue career advancement and progression from HCA to nurse, it is important to find out how the individual came to work in palliative care, a mentally and emotionally demanding job. I will explore the individual perceptions of each HCA, and then summarise a continuous theme within their ideas.

**Susan** is 34 and a HCA who, at every opportunity, will volunteer for vocational training courses to become a more competent

professional. This has earned her the reputation of holding the most vocational qualifications of all HCAs employed at the hospice. When I asked her how she started her career in this sector, she explained that she previously worked in an adult hospice for several years, so she had the work experience necessary for the position she currently holds. A few minutes into the interview, she disclosed that a family member used to come to the hospice as a patient and that's how she heard about the place. When I asked Susan why she didn't want to progress to become a nurse, she simply said:

I want to spend the most time I can with the children, I want to play with them, but I also want to be able to give them the best care, that's why I make sure my skills are up-to-date, and my current job allows me to do that. They keep asking me to do my nurse's training, and I keep telling them no, it's not for me.

Susan said that she had been through a lot of personal bereavement and therefore is "immune to the pain" of upsetting situations encountered at the hospice, as pain is something "you just get used to," adding that she can easily detach from all that's going on.

Gerow et al. (2010) conducted interviews with nurses and found they create a 'curtain of protection' to ease the grieving process, which allows them to continue to provide care for other patients, which may well be what Susan does. However, she is adamant she doesn't want to be a nurse because she perceives that it will reduce her capacity to care for the children.

Susan said she could never go back to working with adults now, because it is more challenging: "Adults are very upset, especially in a hospice, and sometimes you don't feel good or like you're helping, but with the children, I feel like I'm making a difference."

This comparison between children and adults in palliative care allowed me to reflect on the environment. I had completed a week's work experience at an outpatients' ward in a local adult hospice previously, and recalled that the adults tended to dwell on their illnesses and

talk about their regrets or unfulfilled dreams, which can be mentally strenuous for the listener. Family members of the patients would occasionally complain about the lack of care provided and financial hardships in providing full-time care. In contrast, every day at the children's hospice was carefully planned with the intention of filling it with joyous moments. For example, photographs were constantly taken to put in each child's 'Memory Box'. I noticed that the parents of the children were also a lot more optimistic and talkative than adult hospice patients' family members. They would regularly spend 15-30 minutes chatting with staff, constantly maintaining a positive mental attitude, even though they led very busy lives, mostly spent in the hospital for their child. Parents regularly supported each other through the hospice's social media pages and some even set up charities to support other sufferers of particular illnesses. This was a stark difference in the approach to care when compared to adult hospices and made me question why these differences in the approach to care exist.

Beasley et al (2015) articulate many of the concepts displayed in this conversation with Susan. They confirm that (adult) patients approaching end of life display traits such as hopelessness, helplessness and depressive moods, which contribute to making this period very difficult for all involved in their care. This study also comments on why people can find it rewarding yet difficult to volunteer in palliative care: "their involvement contributed to their own personal development, and was personally rewarding... [yet] encounters with family members were sometimes challenging. While some were appreciative, others became overly reliant ... [family] were sometimes offended, hurt, and angered" (Beasley et al. 2015, 1419). This echoes Susan's reason for leaving the adult hospice setting and her sense of making a positive difference, the main motivator to stay in her role, at the children's hospice, where parents were continuously appreciative of the care she provided.

Beasley et al.'s work (2015) also highlights differences in family members' attitudes towards palliative centres, with families of adults in hospices tending to take a scrutinizing stance toward healthcare professionals,

whereas the family members of children tend to display gratitude. It is possible that this is influenced by the pro-life stance of the hospice – the parents feel supported in their decision to care for their child no matter what. However, it is also possible that adults residing in hospices, who are presumed to have been fit and healthy as young adults, have had to go through a transformation in identity, including surrendering their independence due to their palliative care needs. Their struggle to come to terms with their change in lifestyle, in which HCAs become their main point of contact, can put an emotional strain on family members as well as carers. Beasley et al. (2015) thus stress the importance and benefits of providing ongoing support for volunteers in these circumstances, as it can ease the difficulties experienced when caring for someone in their end-of-life period. This is reflected in Susan's direct comparison to the adult hospice she previously worked in.

**Fran** is 42 and started her career at 16 through an apprenticeship at a residential care home before coming to work as a full-time HCA at the hospice. She explained:

Working with the elderly is different to working with children – I witnessed many people passing away but I haven't experienced a loss at the hospice in all the time I've worked here – I only just hear a child has passed at hospital, but that's after their sixth birthday, when they've left the hospice, and although unexpected, it is easier to deal with.

I asked Fran what she thought of the hospice end-of-life care support, where staff work closely with a palliative care consultant. She said it's a great service for families, but involves the nurses more than the HCAs as "you can't really play with the children or anything, they are here to pass away peacefully so I don't think I'll be involved much in their care, but the nurses will." When I asked Fran whether she would ever progress onto nursing, she said no, because it's not financially viable and the paperwork side of nursing is unappealing. This shows there are many factors that HCAs need

to consider before they begin work toward a promotion.

Fran mentioned twice that she found death easier to deal with when it did not happen in her direct presence, in comparison to her experience at the residential care home. This suggests that she may be apprehensive about entering an environment where death is the norm again, which may be another reason why she is reluctant to progress her career. It has been documented that nurses caring for patients who are painfully suffering or dying may experience a wide array of negative emotions including trust issues, loss of self, neglect of self and inability to maintain intimate relationships (Figley, 1995), anxiety, anger, and irritability (Lerias and Byrne 2003), and Fran may be trying to avoid such emotions resurfacing. Fran also mentioned that she values 'play' as a key aspect of her current role, which does not feature much in children's end-of-life care, another factor potentially hindering her career progression.

**Marina**, 37, always wanted to work with children, originally as a teacher, so to gain experience working with children, she went for an interview at the hospice and has been here for ten years. She gave up on teaching because she realised that in a school environment, she wouldn't have the same kind of individual interaction with the children:

Here [at the hospice], I can base my day around that child, get that one-to-one effect which gives me the feeling that I've done more that day. You can notice improvements and changes in the child and to be able to tell the family how much of a good day they've had and how emotional and alert they've been – some families feel guilty about using the service, so to reassure them is great.

Marina said she has not ever considered nursing, and explained her reasons as follows:

The nurses don't do one-to-one with the kids – they do the more paperwork and phone calls side of things – I just want the one-to-one

interaction, you get so much more out of it because certain kids have different needs and you get to cater to these differences in your own way. I don't like hospitals, I spent a lot of time in hospitals growing up and I don't want it – this is a relaxed setting like a 'home from home' for the children where they can be comfortable, but the atmosphere at the hospital isn't nice – there, a child comes in ill and either leaves or dies. Here, I get emotional when I find out a child has passed away but because I've had a relationship with them, I can play back the good memories - it's harder to move on in the hospital because you have nothing to help you answer why they died, and you'll feel that way with every person that passes.

Shorter and Stayt (2009) explored nurses' experiences of grief when their patients died, which was reported as being less traumatic if the death was perceived to be a 'good death', an expected death before which they had provided a high standard of nursing care, and if they had formed an attachment with the patient and relatives, which could help in obtaining closure after their death. This finding is significant in the present context because the relationships that HCAs develop with patients and families may help to normalise the death.

As medical students, we are always taught to 'act in a professional manner' and not form relationships with our patients, but I am beginning to realise that I will not be able to provide a high level of empathetic care to my patients without being a compassionate practitioner. For this I need to establish some form of relationship with my patient. Marina has helped me realise that attachment to a child, or in my case, a patient, isn't necessarily a bad thing, and in fact helps with coming to terms with loss and bereavement, something with which many young doctors struggle.

This insight could also explain why the staff feel they rarely experience burnout. Staff know that their mental health is important to being able to provide a high quality of care to the children and are very aware of the signs and symptoms

to look out for within themselves and each other. The staff I interviewed were unanimous in reporting that the hospice was "a close family" and "very supportive."

Again, the recurring theme emerges of the importance to HCAs of being able to spend quality time with the children to engage and strengthen the emotional bond between child and HCA. Tailoring the day around the child leads to positive emotions within oneself and feelings of making a helpful impact on the lives of a child and their family.

**Natasha**, 27, explained her route into palliative care:

My mum is a primary school teacher, and after some experience in a school, I saw how much paperwork there is and didn't want to do it. I started a health and social care course and qualified. I worked as a nanny and in a day nursery. My sister used to work here as a nurse, she mentioned I should apply to work as a nursery nurse (an activity and play leader) but I always thought I couldn't handle the job; it's a baby hospice, I thought I wouldn't be strong enough to do the job! But after some time, my sister convinced me to do it and I got here and it wasn't like anything I expected, it was so nice, and I got the job. After a while I got asked to change to the role of a HCA so I did and I've been here for seven years. I get asked to be a nurse but I always say no – I'm 27 with two kids – university is not an option – I wouldn't say never, but not now.

I asked Natasha to compare her previous role as a nursery nurse to her current role as a HCA:

I like the job I do as a HCA – working as a nursery nurse, I wasn't caring for the kids, I really felt I wasn't getting anything back, now, as a HCA, I can see how much I'm helping, not only the children, but also their families, and I feel good about the positive work I'm doing.



I then wanted to explore why Natasha kept refusing the company's proposal for her to progress to nurse status:

Looking at the nurses here, you can see they just become 'medicine flushers' [i.e. the nurse's only interaction with a child is administering medication] and they're rushed off their feet – they don't have time for cuddles with the kids and this does worry me if I was ever to consider becoming a nurse.

Natasha's passion for helping people, which possibly motivated her to enter the healthcare sector in the first place, is evident from her preference to work as a HCA rather than a nursery nurse, but it comes with heavy consequences. Her comments suggest that what she values most about her job is the emotional attachment with the children, which, from her observations, will be taken away from her if she progresses onto nursing.

As we kept talking, Natasha started to tell me about more sensitive issues relating to her personal experiences, which have also had an impact on her perceptions. For example:

My niece passed away a few years ago. She was supposed to come here, but didn't make it. I do love my job, but I never thought I'd be here because I remember my niece. I've thought about leaving and going to work in McDonald's again or Tesco (a UK-wide supermarket chain) but I'm supported by the team and told my talents would be wasted in such places. If I become a nurse, I would want to work here or somewhere like here. I feel stronger and better able to support the parents after experiencing a personal loss, as the other losses don't affect me as much.

Natasha's fortitude in her role thus seems to come from personal experience, rather than formal training: since HCA is a role that is not subject to mandatory training, HCAs do not get the opportunity to develop their 'emotion skills' explicitly. In contrast, medical students at Durham University are trained in self-reflection

to help recognise and demonstrate an empathetic approach to patients within clinical settings. Students actively monitor the way they treat patients, which should lead to more mindful practice. Being able to maintain an empathetic approach correlates strongly to medical students' mental health and general wellbeing. Lacking access to such self-reflection and mindfulness training, HCAs are potentially at risk of burnout, which can impact all areas of their lives, personal and professional.

Burks and Kobus (2012) examined the relation between altruism in healthcare and feelings of emotional and career burnout, cynicism, decreased helpfulness and decreased patient-centeredness in care. They report that "altruistic ideals and qualities of empathy appear to decrease ...[when] facing increasingly heavy workloads, deal with strenuous demands...[and] increase the likelihood of emotional suppression, detachment from patients, burnout and other negative consequences... as a means of self-preservation" (Burks and Kobus 2012, 319). Although Natasha knows that her mental health is important, especially as a worker in the healthcare sector, the stigma still attached to talking about emotional problems may prevent her from seeking help if needed. This was demonstrated by her stating she was feeling well during her interview, but on the questionnaire, stating she was stressed.

**Ella**, 22, was looking for a job after finishing her degree in early years and disability studies when her cousin working at the hospice as a nurse recommended a job as a HCA. I asked Ella if this was her original plan, and she revealed that during her degree she had thought about applying for a teaching qualification, but very quickly realised it wasn't for her. Nevertheless, she wanted to work with children, and was attracted to the notion of going into children's nursing, but needed some work experience in the healthcare sector to do so. This led to her applying for a job at the hospice. Also, Ella wanted "to see if I could handle this type of environment." At the time of my fieldwork, Ella was waiting to be interviewed for a job as a nursery nurse in another hospice. When I asked her why she was going for a different role, she said "I wanted to do this instead of HCA because you get to lead play

and activities, it has much less clinical aspects but still involves some care”

Ella thought that in the future, she will pursue further study in either nursing or social care:

I want to give myself a couple more years and research around it and know within myself what I want to do. As a nurse, I'll want to work in the community, like here. If social care, I'd want to be a social worker for disabled children and introduce the families to services that will benefit them, this role is a lot more communication based, which is what I enjoy, rather than clinical skills, which is why I'm apprehensive about nursing, but I think I'd really enjoy putting together care plans for the children, which is a huge part of nursing. Finances are not really an issue, so I will do it, I just don't know which yet.

As we were talking, Ella was getting a child ready for bed which involved putting the child in a 'second skin' body suit to prevent scoliosis: "She [the child] has a high threshold for pain, the 'second skin bodysuit' is very painful but she doesn't cry! I actually wish she would cry because I know it's painful and this not crying actually hurts me even more!" This casual, offhand comment reflects many of the themes I picked out during our conversation. Ella appeared to be a very compassionate and empathetic individual. While these characteristics probably influence her career choices, they also mean she gets emotionally attached to the children she cares for, which can be difficult to handle. Research on the implications of delivering compassionate care reveals that compassion and wellbeing among staff are connected (Grant et al. 2013). Compassion benefits both service users and healthcare professionals. Patients rate compassionate staff as more competent and are more likely to comply with their advice, while staff experience personal growth and feelings of fulfilment from the job that help prevent burnout (Grant et al. 2013). As Claxton-Oldfield's (2014) research on volunteer caregivers found, there can be a mutually

beneficial relationship between terminally ill patients, their families and palliative caregivers. In such relationships, patients can receive access to support and care-needs such as emotional support, companionship, and practical assistance, while families benefit from respite, and caregivers can fulfil their professional identity.

**Nina**, 41, is in her second year of nursing. She currently works part time as a HCA to support her through university. She has worked for four years as a HCA, and eight months at the hospice.

I've worked with elderly in care homes before, but I like working with children more as you feel like you make more of a difference with kids. My main drive going into nursing was my mum who passed away three years ago. I've been interested in nursing for many years and with mum passing away, I said if I don't do it now, I never will.

When I asked whether she preferred working in a hospice setting or the hospital, her opinions made me question whether the interaction between staff and patients in hospitals are hindering recovery rather than enabling it.

Healthcare professionals in the hospital are resilient and stone-faced – I worry about becoming like this and that's why I'd want to work in the community. If I found myself becoming like that, I'd know it's time to leave. Care provided in the community is more real and effective. The ward is very complacent and patients feel like a hindrance for being there, for example if you go in because you have a temperature, the nurses don't think it's a big deal and tell you to go home, it's a very dismissive style of treatment. In the community, you build more relationships with the families, but in the hospital, they're in and out by your next shift, you don't even know what happened to them most the time and when you ask, people don't care enough to know.

I've never experienced bereavement here – in the hospital on placement, a new-born baby passed away. I was there for the birth and everything from that moment was traumatic, I still can't comprehend it. With the elderly, you know they've had a good long life, but this was a new-born. A death here would affect me more than [on] the ward because you know the families, but the team are all so supportive so it would be so much better. You might not get that on the ward – here you always work with the same girls, the ward is all shift work and you may never be with the same people. I didn't get much support for the neonatal death I experienced. Here, there are relationships with families and colleagues, and you look out for each other – there's room for adaptation here, you can tailor-make things for each child and situation, and you're more in control. Here it's centred around the child but the hospital just doesn't provide this type of care.

It has been found that a supportive environment, alongside an understanding of how to recognise and manage bereavement, can help avoid burnout (Dorz et al. 2003) and compassion fatigue (Abendroth and Flannery 2006), ultimately leading to greater resiliency. This support system has been effectively put into place at the hospice. The same is not reported for the National Health Service (NHS), however, where rates of suicide amongst healthcare professionals are continuously increasing.

Again, it appears that believing in a 'good death' and feeling that you, as a healthcare professional, delivered the best possible care are critical for gaining closure on the event. This seems to be important for good mental health and morale among staff, which in turn helps them continue to provide high quality care for patients. This idea is illustrated by Nina's sense that she would leave the profession if she felt she were becoming "resilient and stone-faced".

**Isabelle** is 23 and, although the hospice does not accept students on work experience placements any more, this is how she originally became a HCA. She will start a nursing degree in September:

Working here has encouraged me to take this next step as I feel there is only a limited amount of care I can get involved with, being a HCA; I want to help the children as much as I can. I think I will do child nursing too. The company supports my decision and I can take time off work to go to university and placements – this applies to all staff.

It is interesting to see that some HCAs find their work more rewarding by providing emotional support to the child, whereas others see this as 'limited' to only emotional support. Alongside this, some do not want the added responsibility of being accountable for the care of the patient whereas others see this as the definition of providing care.

### **Putting it all together: my analysis**

During interviews, most staff disclosed that the reason they work in palliative care was due to experiencing someone close to them pass away and wanting to give back some form of the support they received. They all reported feeling better working in palliative care because they felt like they were making a difference, but this was mostly recognised as being specifically linked to working in children's palliative care.

A study among hospice palliative care volunteers by Claxton-Oldfield and Claxton-Oldfield (2012, 525) found that "feeling appreciated by the patients/families they support gave [volunteers] great satisfaction.... They continue because it makes a difference/ helps others/meets a need in other people's lives." This echoes the reasoning I heard in the hospice. All the HCAs agreed that making a difference through their work was the most important factor of their job. However, some HCAs saw their crucial work as being the emotional bond formed with the children, whilst others saw it as the clinical care the hospice was providing – and this seems to be the determining factor for career progression. If

a HCA fears that their emotional attachment and interactions with the children would be jeopardised if they became a nurse, they are more likely to decline opportunities for promotion, expressing that it is in fact this emotional attachment that keeps them strong and motivated to continue to work in the hospice. However, if the HCA values the clinical side of care relative to the emotional side, they are more likely to seek promotion to become a nurse.

This finding ties in with Hochschild's "appreciative starvation" theory (2003), which states that emotional labour is often unrewarded and unrecognised. HCAs are declining promotion in the belief that what they find so personally rewarding in their current position – the emotional labour – will be overshadowed by an overwhelmingly high number of other responsibilities as a nurse.

At times, it almost seemed to me that nurses see patients, whereas HCAs see people, an impression that resonates with previous research (McCance et al., 1999; Perry et al. 2003). Motivations to pursue promotion include better pay, good working hours and realistic responsibilities. Yet no HCA mentioned more money as a reason to seek promotion, even though they could be earning up to three times their current wages. Their responses suggest that they all prioritised job satisfaction and kept in mind what they valued most in their current role: the quality time spent with the children.

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## References

- Abendroth, Maryann, and Jeanne Flannery. 2006. "Predicting the Risk of Compassion Fatigue." *Journal of Hospice & Palliative Nursing* 8 (6): 346-356.
- Beasley, Elizabeth, Joanne Brooker, Narelle Warren, Jane Fletcher, Christopher Boyle, Adriana Ventura, and Susan Burney. 2015. "The Lived Experience of Volunteering in a Palliative Care Biography Service." *Palliative and Supportive Care* 13(05): 1417-1425.
- Burks Derek, and Amy Kobus. 2012. "The Legacy of Altruism in Health Care: The Promotion of Empathy, Prosociality and Humanism." *Medical Education* 46: 317-325.
- Claxton-Oldfield, Stephen, and Jane Claxton-Oldfield. 2012. "Should I Stay or Should I Go: A Study of Hospice Palliative Care Volunteer Satisfaction and Retention." *American Journal of Hospice and Palliative Medicine* 29(7): 525-530.
- Claxton-Oldfield, Stephen. 2014. "Hospice Palliative Care Volunteers: The Benefits for Patients, Family Caregivers, and the Volunteers." *Palliative and Supportive Care* 13(03): 809-813.
- Dorz, Stella, Caterina Novara, Claudio Sica, and Ezio Sanavio. 2003. "Predicting Burnout Among HIV/AIDS And Oncology Health Care Workers." *Psychology & Health* 18(5): 677-684.
- Figley, Charles R. 1995. "Compassion fatigue: Towards a new understanding of the costs of Caring." In B. H. Stamm (Ed.), *Secondary traumatic stress: Self-care issues for clinicians, researchers and educators*, 3-27. Lutherville, MD: Sidran Press
- Gerow, Lisa, Patricia Conejo, Amanda Alonzo, Nancy Davis, Susan Rodgers, and Elaine Williams Domian. 2010. "Creating A Curtain Of Protection: Nurses' Experiences Of Grief Following Patient Death." *Journal of Nursing Scholarship* 42(2): 122-129.
- Grant, Louise and Gail Kinman. 2013. "'Bouncing Back?' Personal Representations Of Resilience Of Student And Experienced Social Workers." *Practice* 25(5): 349-366.
- Hayes, Lauren J, Linda O'Brien-Pallas, Christine Duffield, Judith Shamian, James Buchan, Frances Hughes, Heather K. Spence Laschinger, Nicola North, and Patricia W Stone. 2006. "Nurse turnover: a literature review." *International Journal of Nursing Studies* 43(2): 237-263.

- Henderson, Angela. 2001. Emotional Labor and Nursing: An Under-Appreciated Aspect of Caring Work. *Nursing Inquiry* 8(2): 130-138.
- Hochschild, Arlie Russell. 2003. "Behind Every Great Care Giver: The Emotional Labour in Healthcare." In *Emotional and Interpersonal Dimensions and Healthcare Services: Enriching the Art of Care with the Science of Care*, edited by Laurette Dubé, Guylaine Ferland and Debbie S Moskowitz, 67-72. Montreal: McGill-Queen's University Press.
- Hochschild, Arlie Russell. 2012. *The Managed Heart: Commercialization of Human Feeling*. London: University of California Press.
- Together For Short Lives. 2016. "Information About Together For Short Lives." *Togetherforshortlives.Org.Uk*. Accessed January 10, 2018. [http://www.togetherforshortlives.org.uk/about/who\\_we\\_are](http://www.togetherforshortlives.org.uk/about/who_we_are).
- Lerias, Doukessa and Mitchell K. Byrne. 2003. "Vicarious Traumatization: Symptoms and Predictors." *Stress and Health* 19 (3): 129-138.
- Lutz, Catherine and Lila Abu-Lughod. 1990. *Language and the Politics of Emotion*. Cambridge: Cambridge University Press.
- Mann, Sandi. 2005. "A Health-Care Model of Emotional Labour: An Evaluation of the Literature and Development of a Model." *Journal of Health Organization and Management* 19(4/5): 304-317.
- McCance, Tanya V, Hugh P McKenna, and Jennifer RP Boore. 1999. "Caring: Theoretical Perspectives of Relevance to Nursing." *Journal of Advanced Nursing* 30(6): 1388-1395.
- McCambridge, Jim, John Witton, and Diana R. Elbourne. 2014. "Systematic Review of the Hawthorne Effect: New Concepts are Needed to Study Research Participation Effects." *Journal of Clinical Epidemiology* 67(3): 267-277.
- Monahan, Torin, and Jill A. Fisher. 2010. "Benefits of 'Observer Effects': Lessons from the Field". *Qualitative Research* 10 (3): 357-376.
- NICE. 2011. "End Of Life Care for Adults | Quality-Statement-5-Holistic-Support-Social-Practical-And-Emotional | Guidance and Guidelines | NICE". *Nice.Org.Uk*. Accessed January 10, 2018. [The JUE Volume 8 Issue 1, 2018](http://www.nice.org.uk/guidance/QS13/chapter/Quality-</a></p></div><div data-bbox=)

statement-5-Holistic-support-social-practical-and-emotional.

- Perry, M., I. Carpenter, D. Challis, and K. Hope. 2003. "Understanding the Roles of Registered General Nurses and Care Assistants in UK Nursing Homes." *Journal of Advanced Nursing* 42(5): 497-505.
- Rosaldo, Michelle Z. (1984) "Toward an Anthropology of Self and Feeling." In *Culture Theory: Essays on Mind, Self, and Emotion*, edited by Richard A. Shweder and Robert. A. Levine, 137-157. Cambridge: Cambridge University Press.
- Shaw, James A. 2016. "Reflexivity and the "Acting Subject": Conceptualizing the Unit of Analysis in Qualitative Health Research". *Qualitative Health Research* 26(13): 1735-1744.
- Shorter, Melanie, and Louise Caroline Stayt. 2009. "Critical Care Nurses' Experiences of Grief in an Adult Intensive Care Unit." *Journal of Advanced Nursing* 66(1): 159-167.
- Staden, Helen. 1998. "Alertness to the Needs of Others: A Study of the Emotional Labour of Caring." *Journal of Advanced Nursing* 27 (1): 147-156.
- Williams Simon, and Gillian Bendelow. 1998. *Emotions in Social Life: Critical Themes and Contemporary Issues*. London: Routledge.



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