Janet - Presentation

Janet Underwood:
Hi, my name's Janet Underwood and I'm a part-time PhD student here at the Open University. And I'm approximately half way through my course now. I'm researching the hospital visitor experience and my interest has aroused both by my experiences as a patient and as a visitor but also as a nurse on a busy NHS hospital ward. My PhD is titled Just a Bunch of Grapes.

I consider that my research is important because it's the shear number of complaints that the NHS has to deal with on an annual basis. If you look at the statistics in the year 2012 to 2013 there were 17.7 million finished hospital consultant episodes and there has been no account of the number of people that have visited patients in hospital.

Litigation-wise there were 14,761 cases that went to court. The NHS hospital and community services dealt with nearly 110,000 written complaints in that year and the largest proportion were from hospital inpatients and that was approximately 35,000. The next largest proportion was from hospital inpatients. And finally the next one after that were classed as Other and that is NHS Walk-in centres, NHS Direct and ambulances services and such like.

Also the existing knowledge in this country is very scarce. There's been a little bit of quantitative research and there's also been qualitative research overseas in America and also in Finland. However, I'm very well aware that the NHS culture is very different in this country to say the American healthcare system.

My research has taken quite a long winding path. It started off with getting ethics clearance and part of the condition of having ethical approval was that I had at least 10% of my participants coming from underdeveloped countries or for whom English wasn't their first language. I then did a pilot study with just two participants and this gave me the opportunity to have a go at interviewing. I really hadn't had much experience of that. And it also gave me an awareness of what questions might be pertinent to ask my future participants.

Recruitment actually became a bit of a problem. I had anticipated being able to recruit from my work environment. And I did get approval from the hospital Trust to do this but they wouldn't relinquish Intellectual Property Rights which I was advised would mean that possibly I wouldn't be able to publish any of my results. So I had to recruit in the community. And I did this by placing posters in places like surgeries, Churches, village news, magazines, etc. And I also did it by word of mouth. So I think people got a bit fed up of me saying, oh have you visited somebody in hospital recently. And then by snowballing, asking people if they could pass on to people they knew.

So this recruiting ended up in me finding 16 participants, five men and eleven ladies, all adults obviously. And I was a little bit concerned about the discrepancy in numbers but what I found was that the ladies were much more enthusiastic about telling me about their hospital experiences. And the men were a lot more reticent. And I was actually told that this could be treated as a finding of the research and not to worry about it. My interviews were all semi-structured and voice recorded. And then I transcribed them verbatim.

What I began to notice as I was sort of transcribing and beginning to sort of thematically analyse them was that there was one core theme coming out time and time again. And this theme bore very distinct relationships to liminality. Liminality is coined by Van Gennep and Turner. Van Gennep actually coined the term when he was studying tribal rights of passage. And the work was expanded by Turner.

And basically liminality is that position of betwixt and between in any transition. So what Van Gennep was noticing in the tribes was that, say for argument's sake it was pubescent boys who were going to become men, treated as men in the tribe. They would be separated from the tribe. They would all be together and they would be assigned various tasks, etc. And they would then be reincorporated in the tribe as men. They had been transformed from boys to men and that period in between is the threshold experience called liminality.

Liminality is often overseen by a Master of Ceremonies in the tribes. And I suggest in this case that it's actually the nurses who oversee the visitors in their liminal positions between being in their normal routine world of the everyday and suddenly becoming hospital visitors. There's a sense of communitas. We're all in this together. And visitors will often tell me how they looked out for somebody else's patient if their relatives weren't there.

Another thing which is quite distressing is the sense of invisibility that is very much in Van Gennep's work but was also experienced by my participants. One of my questions was how do you think the staff in the hospital saw you. And the stock reply was, I don't think they saw me at all really. That's quite sad.

There's an anti-structure where the normal rules and regulations are suspended and people are having to live by another set of rules that they're really not quite sure of. And this makes it a time of uncertainty because they don't know quite what's expected of them. They can't find out or they don't know what the prognosis, the diagnosis or the illness trajectory is going to be.

And then there's the transformation when the patient is either discharged or dies. So the transformation can be for good and it can be for bad. For instance I've had a participant whose mother had a hip replacement and then left hospital much more

mobile and free from pain. But I've had other participants who have faced the death of a loved one and a change in family dynamics.

So I had liminality as my sort of core theme. And I was quite interested in the phenomenological analysis. And I was sort of reading around the various philosophies underpinning phenomenology. And I came across Van Manen's work and he suggests that there four what he calls existentials that pervade most human experiences. And these are temporality, corporeality, spatiality and relationality.

So I'll do temporality first and this really came out because all of my participants were talking about the time factors involved in hospital visiting. First of all they had conflicting demands on their time. Their normal routines at home, their domestic tasks and their employment carried on regardless and they had to find time to visit, sometimes travelling quite a lot of distance. The hospital in the meantime had the power and the control of time. They said when people could visit and how long people could visit for. They also charge people to visit because they have put in car parking charges which visitors actually really say is unfair. They think it is a tax on their visiting and a tax on illness.

So this meant that the visitors were actually having a financial loss in the time that they were visiting. Once they actually got to the ward they very often had to wait to see their significant other because the hospital will have decided to have taken the patient for an X-ray or for a test or for a procedure. They would have to wait for a doctor. If they wanted to speak to a doctor and there were no doctors available to talk to them at this particular time. And all the time they were going in and out of the hospital feeding the car parking machine.

And this waiting also made them even more uncertain and anxious and really not at all sure about what was going on while their domestic tasks and responsibilities were piling up at home. I've just put on my slide, this is from a participant and I think it illustrates the existential factor of time. It's about a mother who was dying in hospital and she didn't know that there were facilities available for her to be able to bring her dying mother home for her to be cared for in the home until just four days before she died. She could have had her at home a fortnight before she died. And as she says time is so very precious then.

Spatiality has been quite interesting because a lot of my participants have found that they just couldn't find their way around the hospitals despite the signage. One of my participants said, you know I'd follow the signs and then they'd just disappear. I have to backtrack and pick up the signs again. And the appearance and the comfort of the buildings were also very important. And alongside that I would also say that the hospitality they encountered wasn't always as it really ought to be. A lot of them mentioned a cup of tea. And I kept thinking what's this cup of tea about? And I realised it's the hospitality. They don't receive it.

And then there's the rules of the ordering and control of space which is totally belonging to the hospital. And I had one participant who his every movement from the moment he set foot in to the hospital was controlled. He was controlled by his wife who told him where to go. He got to the ward to see his mother and he was told where to sit. If a nurse came to do anything with his mother he was told to get up and wait outside. And even when it came to discharge he was told to run an errand to pharmacy because the medication that had arrived was wrong. So every single movement he made was controlled.

And as you can see here there's a couple of quotes. But I think Liz's is particularly nice because she says, "It was like being on a parallel planet. It's like being in a space station". I don't think she'd really ever been on a parallel planet or a space station but it sums it up nicely really.

Corporeality. In this my visitors perceived that their own physical needs were often overlooked by the hospital and indeed even within the family or in the network became secondary to the patients physical needs. And they found this quite hard to cope with because they had needs of their own as well. I had one lady, she was disabled, needed a lot of help and support from her family. Could get around the house with the help of furniture but outside of the house she needed a wheelchair. And she became quite poorly in the ward and there was a lady doing the tea round and she said, "Could I have a glass of water please. I don't feel very well." And she was given a glass of water as it says there and then she followed it up by "That's fine". And I felt that that's fine meant that she really had hoped and had wanted a cup of tea but it just wasn't there and offered.

And as Gill says, "Nobody else is going to look after me and certainly nobody in the hospital is concerned about me". And I think that's it. And Jane who I've quoted there. Her husband was rushed in to hospital at 2 o'clock in the morning at the point of death. He went through A&E and they were transferred to another hospital about 12 o'clock midday. And she stood by his bedside until 10 o'clock at night and nobody even offered her a chair. I think that's quite sad.

Relationality. From this point of view there are obviously several relationships going on. There's obviously the family network. And what I found was this, was a lot of drawing together for support as my quote there says from Sue, they really drew together and there was a lot of overseeing of what was going on. The family wanted to know what was happening and they were asking a lot of questions but also they didn't trust the nursing staff and the doctors were actually going to care for their loved one in the way that they hoped. But there was also a hierarchy in the family as well.

So the spousal partner was the sort of the prime visitor. Then the children, adult children followed by wider family. Then they had relationships with hospital staff and

this was predominantly with nurses. Some pulled on their own support networks like friends or work colleagues. And through all of these relations the visitor's roles and identities were uncertain and changing. They weren't sure how they were being seen, what they should be doing and also they weren't sure what role and identity they were going to have post discharge. Were they going to have to give up a job to become a carer? What responsibilities were they going to have? I had one lady who lived in a massive house and they knew that they'd got to downsize so that her husband could manage a much smaller garden. And all these sort of things are going on at the same time as everything else.

And my 'to do' list. I still have one more interview to complete. My sixteenth participant had agreed to do it about her hospital visits to her husband over a long period of time. He has a chronic illness and he was rushed in to hospital for emergency surgery a few weeks ago. And so I haven't really bothered. I'm waiting for her to let me know when it's convenient to talk.

I want to look at photographs and/or media representations of hospitals and hospital care. I haven't actually – this surprises me but policy documents, there is no policy coming from the government on hospital visiting. The Department of Health have nothing to say about it, it is entirely up to the hospital Trusts to set their own visiting agenda.

No patient in this country has a legal right to receive visitors and no visitors have a legal right to visit. And that is quite amazing at the State really. And also I want to look at leaflets and examine those and see what sort of discourses are prevailing. I want to do further reading particularly on the four existentials and phenomenology to further inform my analysis.

All the way through my PhD I have been doing writing exercises in preparation for the thesis. So writing is obviously there. And then hopefully one day I might even submit. And if anybody's interested there's some pertinent references of the people that I've cited and also some existing literature on hospital visiting.