

The Real Story: Palliative Care patients' experience of one acute hospital

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Background

In order to deliver high quality, patient-centred, safe and efficient end-of-life care, it is imperative for service providers to understand what patients think about the care they receive.¹ This is in accordance with the overarching principles of the NHS Constitution and UK National guidance in end-of-life care.^{2,3} Engaging with service users can also inform ongoing service improvement strategies.

Aims

Within one acute hospital trust, to:

- Explore patient experience of being in hospital and receiving support from the Hospital Specialist Palliative Care Team (HSPCT);
- Make recommendations to the acute trust regarding ways to improve patient experience.

Methods

A phenomenological approach was adopted, specifically undertaking:

- Narrative Interviews - with recently discharged palliative care patients;
- Medical case note reviews - key documentation from most recent in-patient episode;
- Thematic Analysis; key themes generated, using the "substance of the interview" to interpret "meanings and perceptions".⁴

Results

20 interviews completed.

Within the main themes; positive experiences were described by many patients:



Care delivery was compassionate and responsive:

"...it's just little things...that make a difference...they wanted to be there, they wanted to care. You could tell that they wanted to care...and they made time for me...they just seemed to care...to want to be there and help" (P24)

"...the majority of the nurses...they were absolute angels. They looked after me so well. They cared for me so well and the young girl (name) who was starting out in her career, please, please try and retain her because she has already the skills that are required from what I can see to be one of the best nurses in the world and those skills are skills with the patients...she was friendly, she was willing to hold my hand and give it a squeeze when it needed a squeeze...and it was just an absolute eye-opener that somebody with two days, three days, four days experience of being a nurse in a hospital, it was just truly breath-taking." (P9)

Patients felt at the 'centre' of care delivery:

"I know that there's issues in the NHS with what they go through...they cope as best they can...they make the most of [organisational facilities and pressures] and they do try and look after people as best they can. They do care..." (P24)

"I'd not had that before. I'd had a sort of "hello, my name is [nurse name] and I'll be looking after you", but not in the same way. Not with the same purpose that it was given, it felt as though she really cared about me and that's just magnificent." (P9)

"...It's when they're there with you, you are important...it's you, it's your moment and you've got to make the most of that" (P24)

HSPCT involvement had therapeutic impact; not just a focus on symptom control but holistic wellbeing of the patient:

"Oh the pain relief, they [AHSPCT] were absolutely marvellous...it was like someone waving a magic wand because after I'd seen them for a few occasions, about three times, er, I just, the next time they came to see me, I said it was the first time that I'd slept properly in about six weeks." (P7)

"I felt as though she was that type of person that she was giving." (P15)

"Er, the one thing I do remember is the feeling of being looked after. Nothing too much trouble, you know, they were there for me if I needed them." (P20)

Results (Cont.)

However challenges were evident, with less positive experiences also described:



Over stretched staff and resources:

"...sometimes they were run off their feet. They can't always come so you don't get bad tempered or anything, you just have to wait and know that they will come." (P3)

"it seemed to be more management than care to me...it's like a dam waiting to break, it's all overburdened with bureaucracy, nonsense..." (P25)



Task oriented focus of care delivery:

"she'd come back and make the beds. And then she would be running round...there was a shortage of help and she did seem to have an awful lot to do." (P25)

"that the nurses don't...are thinking solely of their own needs to get the patients through with as little impact as possible on their own time management. And it shrieks that, especially when it comes to high volume admissions units, that that's all that matters to the nurses on those units." (P23)

"Well, you know, when you're expecting tablets for instance, they say you should have them between eight and eight. Well it was about midnight when I used to have them, you know, this sort of thing...and they say, "Ooh we're on our rounds." (P4)



Pain assessment and control was a concern for many:

"Sometimes we ask for medication and they'll say I'll get it for you, and you'd end up getting it eventually when they'd come round with the trolley two hours later..." (P1)

"Erm, it's like you know if someone, they had like, erm, wood and paper and everything and they put a match to it and it went aflame, that's the way I feel, ya know when it hits my right leg...that's how the pain was, and I felt like a fire had gone off inside me." (P3)

"It was quite frightening. And the pain was that bad that it was actually knocking me sick, just feeling sick. And it was like three, four in the morning and I just had to wait all those hours for about three nights until they brought the medication round." (P7)

Conclusion

These patient stories highlight the importance of concepts such as kindness, compassion and dignity. Positive experiences of care were often described in terms of: taking the time to 'care for patients' rather than time to 'do to patients'; taking the time to listen to what is most important; taking the time to respond to the patient as an individual. Where care delivery pays attention to these concerns, it has the potential to create a lasting positive impression for patients.

The palliative nature of patients' illness underlined that there is 'one chance to get it right'.⁵ These findings enabled recommendations to be generated for the acute trust, rooted in 'real' patient experience, promoting local change and improvements to patient care delivery.

References

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