

Table 53: Willard 2006⁴⁷⁰

Study	Willard 2006 ⁴⁷⁰
Aim	Discuss the challenges to appropriate EOL care in acute hospitals in the UK, highlighting how this setting contributes to the patients' and families' care and treatment requirements being excluded from decision-making.
Population	<p>Healthcare professionals:</p> <p>29 cancer nurse specialists from 5 hospital trusts. Eligible CNSs were hospital-based registered nurses, whose roles appeared to involve a high level of expertise within the field of cancer and palliative care. Participants included: 3 nurse practitioners, 2 research nurses, 11 tumour-specific CNSs, 9 palliative care CNSs, 4 CNSs with combined tumour-specific and palliative care roles.</p>

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Setting	UK.
Study design	Grounded theory study using observation and semi-structured interviews.
Methods and analysis	<p>Data collection:</p> <p>Participants were selected according to the principles of purposive and theoretical sampling. Data collection involved 135 hours of observation followed by semi-structured interviews. Some CNSs agreed to both observation and interviews, resulting in observations with 15 CNSs and interviews with 17 CNSs. Observation took place in hospital outpatient and inpatient areas and included observing 73 CNS-patient interactions and numerous professional interactions. Participants were those at various stages of the disease process, from those recently diagnosed with cancer, to those who were in the final stages of their illness. The interviews were tape recorded and lasted between 30-90 minutes.</p> <p>Analysis:</p> <p>Field notes from observation and transcribed interviews were thematically analysed using a constant comparative method used in grounded theory. The qualitative data analysis package NVivo, was used to facilitate data management and analysis. Emerging categories were reviewed by KL and preliminary findings discussed with study participants who were able to attend a feedback session prior to compiling a final report.</p>
Themes with findings	<p>Prioritization of treatment:</p> <p>CNSs reported there was minimal discussion either within teams or with patients, about the overall aim and rationale of treatment.</p> <p>‘I deal with haematology patients as well, and the perception there is that it’s treatment, treatment, treatment, right until, sometimes they don’t actually stop, people die having active treatments, when maybe somebody should have at some point said “Well look, where are we going?”.’ Palliative care CNS.</p> <p>For CNSs, compliance with routine practice was a source of considerable frustration and contradictory to their beliefs about dying well, where comfort and control of symptoms take precedence.</p> <p>‘A lot of my work is in the surgical area, and thoughts are very surgical-moulded, so for example things like intravenous fluids, at the EOL, 3 or 4 litres a day, and they’re actually prompting symptoms such as ascites and fluid overload and breathlessness, because their thoughts are still post-operatively rather than in EOL situations.’ Palliative care CNS.</p> <p>For professionals geared to meeting the demands of treatment, there was a perception that palliative care was ‘giving up’ on the person when there was still much that could be done.</p> <p>‘Rather than palliative care being a good thing, it’s actually seen in a very negative way and therefore kept at a distance. If the language of palliative care is difficult, it may be fair to assume that the language of treatment is quite the opposite perhaps pro-active and positive, there’s more to be done, there is more to be given. It’s still very much this separate camp – them and us camps.’ Palliative care CNS.</p> <p>Prioritizing treatment and routine care also appeared to prevent attention to symptom management and discussion of patients’ views and preferences about their treatment and care, even when there was opportunity to do so due to the person’s expected deterioration.</p> <p>‘We went to see an elderly lady who had metastatic oesophageal cancer and bowel obstruction. She had been in hospital for about a week, was aware she was dying and had put her affairs in order. She told the CNS she wanted to die at home, but ward staff had not explored the</p>

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	<p>practicalities of this or other options of care. The person was still nil by mouth, subcutaneous fluids were being given and analgesia prescribed when necessary rather than regularly.’ Tumour-specific/palliative care CNS.</p> <p>Although in this case the CNS had been able to elicit the person’s preferences, it was too late for these to be acted upon.</p> <p>Critical junctures:</p> <p>Critical junctures are described as points in the course of a serious illness where current treatment could be evaluated in relation to changes in the person’s condition. Critical junctures are not always recognised as opportunities to review and reset the treatment plan to one more appropriate to the person’s deterioration or explore the patients’ or families’ preferences.</p> <p>‘A patient with lung cancer was admitted and had surgery for a suspected space-occupying lesion but it turned out she had brain metastases. The nurses were still continuing to do neuro-obs, and there was a train in the lady’s head. The daughter was absolutely frantic you know, “is she dying?” She was vomiting and she had headaches and you know her treatment was very medicalised really. The family, they didn’t want treatment to continue and wanted to get her off this really busy acute ward where no-one spend any time with them.’ Palliative care CNS.</p> <p>Ethical challenges:</p> <p>While critical junctures provide opportunities to review current treatment plans, they also raise complex and uncomfortable ethical questions about what a person’s deteriorating condition represents and whether it should be treated. A CNS describes how she and the consultant differed in their perception of a situation concerning a very ill person with dysphagia and the most ethical course of action.</p> <p>‘The consultant felt as though he couldn’t let her die in that way, so I just said I thought she was dying, and it isn’t pleasant having a feeding tube put in, they don’t always work, there are complications and the risk of having all that for the outcome, I didn’t feel that it was justified. He could understand where I was coming from and it did make him think about it, but he still was saying well you know we should give it a go.’ Palliative care CNS.</p> <p>Even when people are capable of expressing their wishes, it appears that the treatment ethos of the acute setting may contribute to the paternalistic professional stance, in which the views of certain categories of people may be overlooked and, therefore, excluded from the decision –making process.</p> <p>‘We went to see an elderly man admitted (not for the first time) with bleeding oesophageal varices. The patient looked very ill and frail: he had also been diagnosed with bladder cancer 3 years earlier but had refused treatment. In the medical notes, a treatment plan involving further investigations and surgery for the varices had been documented, but according to nursing staff, the patient just wanted to return home where he lived with his brother. The CNS talked to the patient about the proposed surgery, he was very sure he did not want any treatment that he thought he was dying but had to die of something, and would rather spend his remaining time at home. When the CNS discussed his case with the senior doctor, she said she believed he had been mismanaged in the past and that the proposed surgery was essential. The CNS pointed out that the person was very clear about what he wanted and if he was aged 25 and mobile, he would simply discharge himself. While the doctor accepted this, she was also keen to pursue the banding to prevent further bleeding.’ Palliative care CNS.</p>
Limitations	Serious limitations. Analysis of themes conducted by 1 individual only.
Applicability of	Direct UK setting.

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evidence	