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Dignity in End-of-Life Care

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Helping patients die with dignity is a central part of palliative care. However it means different things for different patients and their families. An initiative to support nurses caring for patients at the end of their lives has been rolled out in rural Scotland and is proving a great success.

End-of-life care is the part of palliative care which should follow when a patient is diagnosed as entering the process of dying, whether or not he or she is already receiving palliative care.¹ To conserve dignity is central for palliative care,^{2,3} but in spite of this, people experiencing end-of-life care often fear loss of dignity.⁴ Dying with dignity has been defined as having one's human value and worth acknowledged, being cared for with respect and empathy, having a voice regarding one's process of dying, minimising physical and emotional suffering, safeguarding one's privacy, being emotionally connected with others, resolving personal affairs, and having access to spiritually sources of support.⁵ However, dying with dignity means different things for different people,^{4,6} shaped by an individual's historical, social and cultural perspectives.⁶ Care, therefore, should be based on holistic assessments of physical, social, emotional, cultural, and spiritual care needs and other relevant life circumstances.⁷ Taking into account all these needs, care should comprise a broad range of activities based on an understanding of what sources of distress that might influence the patient's sense of dignity.⁴

CONSERVING DYING PATIENT'S DIGNITY

A project to develop an intervention to support nurses caring for people at the end of life was initiated by Bridget Johnston, Senior Researcher at the University of Dundee, Scotland, with the collaboration of Ulrika Östlund, oncology nurse at Karolinska Institutet, Sweden, who spent a year in Scotland working on the project, and Hilary Brown, Macmillan nurse in the West Highlands, Scotland. Harvey Chochinov from the University of Manitoba in Canada, known for his important work on dignity in patients with advanced illnesses, supported and helped develop the project. The aim was to develop and implement an intervention, the Dignity Care Pathway (DCP), initiated by the authors, to be used by community nurses in a rural area of Scotland to conserve dying patients' dignity, as well as evaluate the acceptability and feasibility of the intervention, based on experiences from community nurses using the tool.

The Chochinov model

Firstly, in order to develop a theoretical understanding of dignity conserving care, existing studies and theories were scrutinised⁸ in a systematic, narrative review. A model of dignity, developed from

the work of Chochinov et al,^{4,9} was chosen as the framework for developing the intervention. It covers a broad spectrum of sources of distress, and includes three main domains: illness related concerns; dignity conserving repertoire; and social dignity inventory. These domains can be thought of as a therapeutic map, guiding health professionals to structure their care actions with a view to conserving dignity. The model is empirically based on cancer patients' perception of dignity, and is thought to be flexible enough to consider broad application among patients nearing death, acknowledging their personal, unique differences. In order to provide evidence on care actions to be included in the pathway, an approach describing evidence-based practice was adopted, which included not just research evidence but also clinical experience, patients' and carers' knowledge and the local context and environment.¹⁰

THE DIGNITY CARE PATHWAY

In phase 1 of the project, the DCP was developed from a narrative review and from focus group interviews with patients, carers, nurses and GPs to find suggestions on care actions in relation to the Chochinov model of dignity themes. The DCP has been developed so it can be used by community nurses when caring for patients in their end of life, during the whole end-of-life trajectory until the patient's death. The DCP should be used as often as judged necessary by the nurse or requested by patients or carer to deliver ongoing dignity conserving care. The community nurse makes a prognostic, clinical judgment to decide when to start a patient on the DCP.

Reflective questions.
Community
nurses discussing
the pathway.



The DCP consists of three component parts:

1. Patient Dignity Inventory

The first part, the Patient Dignity Inventory (PDI), was developed by Chochinov et al.¹¹ to assess various sources of dignity-related distress. This inventory provides a feasible and reliable way to identify dignity-related distress. Each PDI item is rated on a five-point scale, 1=not a problem; 2=a slight problem; 3=a problem; 4=a major problem; 5=an overwhelming problem.¹¹ In the DCP, it is suggested that items rated 3 or higher should be further explored by the community nurses, in conjunction with the patient and, if agreed, their carers.

2. Reflective Questions

The second part involves Reflective Questions, used to learn more about the identified issues, the patient's ideas and preferences on how to deal with them, and if further actions are needed. Reflective questions can also be an intervention, in themselves.¹² Besides using the questions provided, community nurses are encouraged to use them as examples for developing their own reflective questions suitable for the conversations they are having.

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3. Care Actions

The third part, Care Actions, are intended to be used in discussions with the patient and, with patient's agreement, their family, and undertaken based on the patient's preferences. When the aim is to conserve dignity, it is especially important that patients are given a voice regarding their own care, as a way of treating them as equals, with respect, and to acknowledge their human value and worth.⁵

Finally, community nurses evaluate whether the interventions used have been effective by using the PDI again, if judged appropriate. This helps to maintain continuity, as well as identify issues that have recently arisen. When new concerns are identified, the circle of care will continue using the reflective questions and suggested care actions.

EVALUATING THE DCP

In phase 2, the implementation and use of the DCP were qualitatively evaluated by nurses using the tool. A manual was developed for this purpose describing dignity in end-of-life care, the evidence base of the DCP, and the supposed use of the DCP to deliver ongoing dignity conserving care. An educational programme on dignity conserving care in general and the use of the DCP in particular was conducted. In addition, a session on practising communication skills was carried out, since effective and excellent communication is central for the care actions suggested in the DCP. Community nurses involved in end-of-life care at the study units were invited to participate in the educational programme, to use the DCP, and to participate in the evaluation study.

The first stage of the evaluation of the DCP is ongoing. The current phase involves a qualitative evaluation using multiple methods, including individual interviews, focus group interviews, reflective diary, where the community nurses record significant events occurring during delivery of the intervention, and case studies. User involvement and patient experience have been an important part of this project. Patients and carers have been involved in the development of the DCP and have provided, and continue to provide, useful comments on its development.

Early analysis indicates that all the community nurses have positive and useful comments in regard to their use of the DCP and the training before they used the intervention. Difficulties with using the pathway usually relate to communication issues when the patient is not yet at the stage they can discuss their future and their impending death. After all interviews have been finalised and analysed, the DCP and its implementation will be further developed in accordance with the findings.

All the evidence suggests that the DCP has proved to be a crucial tool for nurses to help them bring out sensitive issues, important for people in their end of life. The reflective questions and suggested care actions can give nurses evidence based means to address distress in a supportive way. If the DCP is shown to be feasible and acceptable for nurses to use, the next stage will be to continue testing the tool and adapt it for use in other cultures in the near future.

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