AIIHPC

All Ireland Institute of
Hospice and Palliative Care

EXECUTIVE SUMMARY

Dignity Care Intervention Ireland

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THE IRISH HOSPICE FOUNDATION

Irish Cancer Society

UCD DUBLIN

THE INSTITUTE OF COMMUNITY HEALTH NURSING

Ulster University

Executive Summary

The overall aim of this service development initiative was to implement and evaluate an intervention delivered by community nurses to help conserve the dignity of people with advanced and life limiting conditions including the frail elderly in community settings. The Dignity Care Intervention – Ireland (DCI-Ireland) project involved a patient-centered assessment to identify and address key concerns in three main domains: **(1) illness-related concerns; (2) dignity conserving repertoire; and (3) social dignity inventory.** The intervention was intended to help nurses to identify what patients and carers consider most distressing for the patient and act as a guide in terms of how this distress may be addressed effectively. An evaluation of the intervention was undertaken to determine the relevance and acceptability of the DCI-Ireland to the local context.

Objectives of the project

The key objectives were to

1. Provide a service-orientated education programme for Public Health Nurses, Community Registered General Nurses, Irish Cancer Society Night Nurses and Specialist Palliative Care Nurses about the Dignity Care Intervention.
2. Implement the Dignity Care Intervention within clinical practice with different community nursing groups in a rural (Limerick and Wicklow) and urban (Dublin) settings.
3. Explore the acceptability of the Dignity Care Intervention based on nurses' perceptions of the content and use of the Dignity Care Intervention.
4. Explore the acceptability of the Dignity Care Intervention based on patients' and carers' feedback.
5. Identify any potential barriers and facilitators to successful implementation and integration into standard community nursing practices for patients with advanced and life limiting conditions.
6. Promote learning arising from this project through the lead and partner organisations/ services/structures including AIIHPC drivers (Education Network, Voices4Care (users/ carers forum) and Structured Research Network).

This project comprised four phases:

Phase 1
Contextualising the DCI Tool to the Irish Context Dignity Care (Scotland) to the DCI-Ireland and preparation for implementation

Phase 2
Educational Programme for Community Nurses

Phase 3
Implementation of the DCI-Ireland Intervention

Phase 4
Evaluation of the DCI-Ireland

Key findings and conclusions

Introducing the tool to patients required a level of confidence in the nurse that the tool was effective and that they had the skills to conduct discussions around the topics that could emerge from implementing the tool.

Overall, both the nurses and the patients were supportive of the tool. In terms of the analysis of the completed tool with the selected patients it is noteworthy that overall, almost 50% of the 25 statements were deemed not to be a problem for patients. The greatest area of concern was the illness related category and specifically physical distressing symptoms (identified as a problem for 24 of the 25 patients). This raises questions about the overall sample selected and inclusion criteria for this study, especially compared to other patient populations internationally. For example, frail elderly were included in this study as they are a core element of the PHN caseload and yet in terms of Dignity Intervention they did not appear to have significant concerns in many of the domains. It is also interesting to note what whilst in the initial stages of the project the nurses expressed concerns about posing certain questions to the patients, for example Question 26, 'worries about how my illness or death will affect my family or friends'-the patients did not identify this aspect as a problem and at interview expressed an openness to discuss such concerns.

The findings of the focus group interviews showed that the nurses were not confident in discussing death and dying, that time constraints were involved due to an ever increasing workload and organisational aspects related to their role and wider integration with other services. The nurses were also cautious about administering the tool to patients because of perceived impact it might have on family reactions. In general, the nurses themselves questioned if they were overly cautious about which patients they picked for the study. All eighteen patients interviewed had been in the services for some time before they were introduced to the tool and were known to the public health nurse.

A heavy workload was the reason given as to why more patients could not be recruited for the study. Not only would administering and explaining the tool take time but the potential consequences of what could emerge from it caused concern to the nurses who reported it could 'open a can of worms'.

Despite this however, it was noted from the online survey results that the majority of the nurses reported that the tool had: a) contributed to the assessment for palliative care; b) initiated discussions with patients and carers that would not normally have happened; c) identified areas of assessment and need that would not normally have been identified; and d) initiated new care for their patient and helped them to get a new insight into the patient perspective.

Recommendations

- There is a need for all nurses working in the community to have further education on talking to patients and families about death and dying and end of life care as many of the nurses reported discomfort with dealing with death and dying and with managing family at this stage of their patient's illnesses
- Further consideration and analysis of the role of the Public Health Nurse (PHN) in relation to palliative care and the palliative care approach is needed given the reported time constraints and their diverse workload
- The patients need for dignity in all aspects of their care needs formal recognition and this can be achieved through assessment using a recognised tool such as Dignity Care Intervention-Ireland.
- Conducting a formal assessment of dignity as part of the overall patient assessment is essential so that issues related to dignity are routinely incorporated into patient care.
- All professions, including health care assistants, working with this patient base need education on dignity conservation using existing resources developed for this project and available from the Palliative Learning Hub.

Project Team

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