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All Ireland Institute of
Hospice and Palliative Care

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Executive Summary

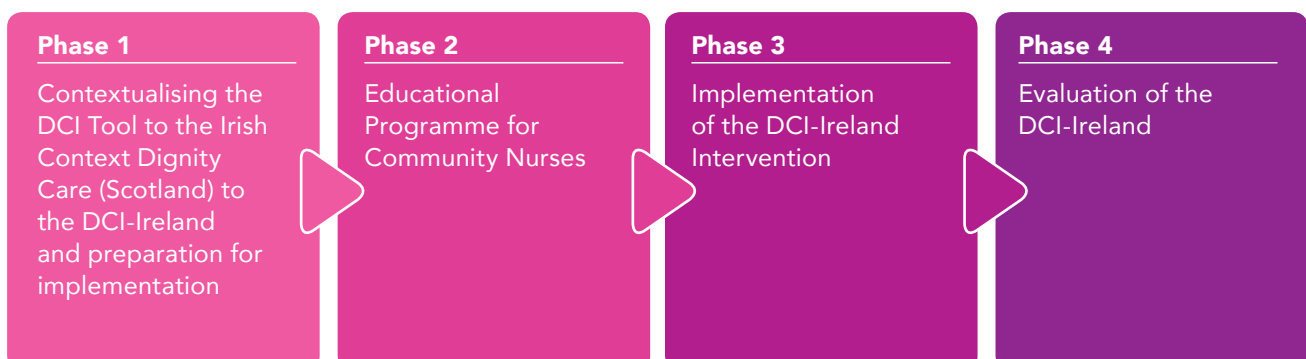
The overall aim of this service development initiative was to implement and evaluate an intervention delivered by community nurses to help conserve the dignity of people with advanced and life limiting conditions including the frail elderly in community settings. The Dignity Care Intervention – Ireland (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:



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.

Introduction

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.

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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-Ireland.
4. Explore the acceptability of the Dignity Care Intervention-Ireland 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 AIHPC drivers (Education Network, Voices4Care (users/carers forum) and Structured Research Network).

Background

People experiencing end of life care fear loss of dignity more than anything else (Chochinov, 2002). What defines dignity for the individual patient and his or her family is unique, and dignity conserving care does not just comprise what one does with or to the patient but also how one sees the patient in their humanity (Chochinov 2002). Dignity is a concept that pervades both health policy and practice as well as lay and biographical accounts of dying. Moreover, a central tenet of palliative care is to help people die with dignity. An empirically based model of dignity has been developed from the work of Chochinov et al. (2002). This framework covers a broad spectrum of concerns inclusive of physical, psychological, social, existential and spiritual sources of distress.

The model of dignity devised by Chochinov (2002) includes three main domains;

- Illness related concerns;
- Dignity conserving repertoire and
- Social dignity inventory.

This model provides an opportunity to develop dignity conserving interventions, as a framework for a patient centred assessment to identify key concerns to make patients' care management more individualised and focused on their main concerns. From a palliative care perspective, the need to provide care which is both responsive and supportive to individualised need is evidenced within the wide body of literature which associates the concept of a good death as one with dignity (Allmark 2002; Seale 2002; Kehl 2006; Mathews 2010). From this model of care, Professor Bridget Johnston and her colleagues in the University of Dundee in Scotland developed a tool to implement, and evaluate the dignity model of palliative care. This was labelled the Dignity Care Intervention (DCI). The tool provides a series of questions to help practitioners explore pertinent issues as perceived by patients in relation to their care and enables them to evaluate the extent to which these issues are resolved or minimised. Previous research by Johnston et al., (2010; 2012) clearly indicated that community nurses found the tool added to the quality of care for patients with palliative care needs across a range of illnesses, chronic diseases and cancer. Brown et al (2011) conducted a qualitative descriptive study in Scotland as one phase of a larger study to test a care pathway which

was intended to conserve dignity at the end of life. Six focus groups were undertaken; two with clinical nurses (N=14), one with GP's (N=3), one with patients, one with carers and finally one with patients and carers (N=13; Patients = 8; Carers = 5) (Brown et al., 2011). They found that patients and family carers reported a greater sense of worth in being respected and listened to by nurses and ultimately, that dying with dignity was achieved (Brown et al., 2011). The Patient Dignity Inventory (PDI) tool designed by Chochinov has also been translated into German and tested on 112 patients to evaluate the psychometric properties of the tool in a sample of cancer patients (Sautier et al. 2014). The study concluded that the tool was a valid instrument for the assessment of dignity related issues at the end of life.

Palliative Care in Primary Care

Palliative care is defined by World Health Organisation (WHO) as an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems. Studies in palliative care report that the majority of people would prefer to die at home (Van Rensbergen et al, 2006; Gomes et al 2010). In line however, with the international literature, however, available Irish survey data suggests that whilst almost two thirds of older people in Ireland would prefer to be cared for at home when dying (O'Shea et al., 2008), the majority (48%) of deaths in the Republic of Ireland occur in acute hospitals (McKeown 2010). This raises important questions for the development of palliative care within primary care setting and the imperative of developing a comprehensive, standardised, quality service for palliative and end-of-life care in primary care in Ireland.

The principles of primary care have been articulated in Irish policy since 1994 (HSE 2001). This means many people are cared for within primary, secondary and tertiary care in their own homes. However, the Irish Hospice Foundation observed that there is currently no guidance framework for community healthcare professionals for palliative care (IHF, 2011). In light of this, the DCI has the potential to offer such guidance around delivery of palliative care in the community.

One of the most prominent healthcare professional groups in the community is that of the Public Health Nurse (PHN). Unlike the General Practitioner (GP), the PHN practices within a population-based-geographical caseload. This involves working within a primary care team and health and social care networks to provide comprehensive care to clients. In terms of palliative care, PHNs have links with the Specialist Palliative Care Community Team. Up to 30% of Directors of Public Health Nurses report that they hold responsibility for palliative care services (Office of Nursing Midwifery Services Directorate (ONMSD), 2012). However, the ONMSD (2012) survey reported that Directors of Public Health Nursing (DPHN), who do not have responsibility for palliative care services can have varied links with formal palliative care services, which range from no communication to joint monthly meetings. Despite this somewhat spurious relationship, adult palliative care is reported to be fully assessed and co-ordinated by PHNs, many of whom work in partnership with the community registered general nurse and the specialist palliative care nurse. This partnership is also highlighted by in the Primary Care Strategy for Ireland (Department of Health and Children 2001).

In considering the reality of community nursing related to palliative care, it is apparent that standardisation of services is desirable. This demands that an appropriate palliative care ethos is used by community based staff (DOHC 2001; DOHC 2009; IHF 2005). Moreover, additional education is required within all levels of palliative education to ensure a quality based, equitable service. Through a process of service engagement, education and evaluation of the DCI in practice, the proposed project builds on existing professional nursing links to develop stronger and more cohesive partnerships for better palliative care in the community.

Dignity Care Intervention Tool (DCI)

The tool provides a series of questions to help practitioners explore pertinent issues as perceived by patients in relation to their care and allows them to evaluate the extent to which these issues are resolved or minimised. More specifically, patients are asked to consider which issues, out of a possible 26 items, are most important to them and problematic. Items may be rated from 1 (not a problem) to 5 (an overwhelming problem). Following this, the nurse practitioners¹ posed a series of questions to patients in order to explore and evaluate change. A full copy of the tool is included in Appendix 1.

¹ The term nurse is used in this report to include the PHN and the RGN where there is a need to differentiate between the two grades the exact title is used.

Project Phases

There were four phases to the DCI-Ireland project.

Phase 1: Contextualising the DCI Tool for Ireland

Phase 2: Educational Programme for Community Nurses

Phase 3: Implementation of the DCI-Ireland Intervention

Phase 4: Evaluation of the DCI-Ireland

Phase 1: Contextualising the DCI tool for Ireland

Phase 1 involved the identification of possible pilot sites and the establishment of the Project Team (Appendix 2), the Steering Committee (Appendix 3) and an Expert Advisory Panel (Appendix 4) to oversee and review the adaption phase of the DCI-Ireland. From the education perspective the Dignity Champions and the Education Co-facilitators were selected and a field trip to Scotland was undertaken to meet with Prof Bridget Johnston, Expert advisor DCI and the Dignity Care Pathway project team in Scotland. Following this visit, the service orientated DCI educational package was developed. The process of adaptation of the DCI to an Irish context was informed by three key stages:

Stage 1: An updated integrated review of the literature on dignity-conserving care in palliative care settings was conducted. This was published in Journal of Clinical Nursing (Johnson et al 2015).

Stage 2: An Expert Advisory Panel was established to oversee and review the adaptation phase of the DCI-Ireland project. The Expert Advisory Panel was made up of representatives from Education, Clinical Practice, Practice Development and Management.

Stage 3: Four pilot sites were identified for the project. These four sites are a mix of both urban and rural Public Health Nursing Services. Two of these were rural area and the other two were urban centres (Table 1). Each pilot site is made up of individual networks that function independently as Primary Care Teams. It was decided for the purpose of the project to include one network per pilot site area as it was outside the scope of the project to include all community nurses for education, training and support throughout the pilot project.

| | | Population | PHN | RGN |
|--------|-------|------------|-----|-----|
| Site 1 | Urban | 42,254 | 11 | 4 |
| Site 2 | Urban | 34,043 | | |
| Site 3 | Rural | 55,101 | 15 | 10 |
| Site 4 | Rural | 30,868 | 9 | 2.4 |

Figure 1: Profile of the Pilot Sites

Each of the four pilot areas were served by a team of nurses headed up by an Assistant Director of Public Health Nursing (ADPHN). Within the project this person was responsible for the roll-out of the pilot project in his/her area. A second person was nominated by the project as a dignity champion. In some areas two champions were nominated. The champion was someone with additional palliative care knowledge and skills and who would promote the project and act as support and point of contact for the community nurses.

A series of 3 focus group discussions were held with public health nurses across three different geographical regions (n=18), and one focus group discussion with user/carer representative (n=10). The purpose of these was to further inform the contextualisation process and refinement of the DCI-Ireland tool, specifically focusing on relevant care actions. At this stage the project was submitted and approval gained from UCD Ethics committee.

Phase 2: Educational Programme for Community Nurses

A targeted education programme for the Dignity Care Intervention Project was developed for the community nurses in the pilot sites to prepare them to implement the DCI-Ireland tool. The DCI-Ireland Educational Package consists of a blended learning approach. This included an ELearning Introductory Module including:

- Background information on the DCI Ireland project
- Introduction to the concept of Dignity
- Introduction to the DCI Tool
- Principles of Communication in Palliative Care
- Suggested further reading materials.

This component is hosted on the AIHPC website at: <http://aiihpc.org/palliative-hub/learning-platform/>.

Train the Trainer workshop (6 hours)

A six hour 'Train the Trainer' workshop was delivered to the Education Co-Facilitators and Dignity Champions for each pilot site. The Train the Trainer programme and membership of the Dignity Champions and Education Co-Facilitators are outlined in Appendix 5 and 6 respectively. An evaluation was carried out on completion of the 'Train the Trainer' programme and this feedback was used to inform the Education programme for all other participants. Continuous Professional Development, Category 1 approval, was awarded (5CEUs) by the Nursing and Midwifery Board of Ireland (Bord Altranais agus Cnáimhseachais na hÉireann) for the 'Train the Trainer' programme (Appendix 7).

Interactive DCI-Ireland workshops (2 x 3 hour skills development)

Further interactive DCI-Ireland education workshops were provided to each of the DCI-Ireland pilot sites for all community nurses taking part in the pilot project. These workshops focused on exploring:

- The role of the Dignity champion and Education Co-Facilitator in practice;
- The DCI-Ireland materials and training manual;
- Practical application of the DCI-Ireland tool, explored through the use of role play and case studies;
- The principles of communication skills; clinical assessment skills and clinical decision making;

- The process of recruitment and consent to take part in the pilot project
- Category 1 approval was awarded (6CEUs) by the Nursing and Midwifery Board of Ireland (Bord Altranais agus Cnáimhseachais na hÉireann) for the DCI-Ireland Education programme. The training was delivered to nursing staff of each of the four pilot sites.

Evaluation Educational Programme for Community Nurses

The educational package was evaluated following roll-out among the community nurses. Pre and post education questionnaires were employed to measure the impact of the educational offering. The surveys were completed by all nurses who participated in the DCI-Ireland workshops. A quantitative descriptive design method was employed to evaluate the educational package on the participants and the data was analysed using the SPSS V20 package.

Findings from the evaluation of the education programme indicated that in general, community nurses were aware of the principles of palliative care but had some difficulty articulating their use in practice. Overall nurses who completed the education programme felt their knowledge and understanding of the principles of palliative care and their application in practice as well as the importance of dignity preserving care was improved.

Phase 3: Implementation of the DCI-Ireland Intervention

Context

The participants in the evaluation phase of the project were the Public Health Nurses (PHN) and Registered General Nurses (RGN's) working in the community as well as the patients and/or their careers that completed the tool. The implementation of the DCI-Ireland tool in the two urban areas was predominantly carried out by the Community RGNs whilst in the two rural areas this was more likely to have been completed by a PHN. One explanation for this related to the work systems. PHN's deliver childcare services for under 5's, maternity services and older person services. In contrast the RGN in the community tends to have the sole remit of care for the older population. The PHN usually manages the caseload for an area and delegates the care of the older population to the RGN although in some areas the RGN manages their own case load comprising solely of older people. RGN'S can normally conduct assessment on older people. In all cases the RGN reports to the PHN.

There does appear to be fluidity in the definition of the role of the RGN in the community as this is a relatively new phenomenon and the methods of operating RGN workload differs from area to area depending on staffing numbers, population needs and case profiles.

Meetings with the sites

During the implementation of the DCI-Ireland tool by the four pilot sites continual backup was provided and regular meetings of members of the project team and the relevant nurses took place. Each site had a minimum of two visits by members of the project team seeking to reinforce the use of the tool, to offer support and guidance on choosing participant and to discuss any issues that arose in relation to using the tool. A discussion board was also provided via the AllHPC Learning Platform but it should be noted that the nurses did not really engage with this method of communication.

It is also important to note that during the lifetime of the project there were various changes in staffing with some of the Dignity Champions, ADPHN and staff moving between sites. This had some implications on overall update and data collection.

Demographics of patient participants

The inclusion and exclusion criteria were discussed with three different groups, Voices4Care², the Education Co-Facilitators and Dignity Champions, and the project Steering Group. The criteria for selection of the patients included:

- A. Patients living at home with a chronic life-limiting condition, this also included the frail
- B. Having a family member as their main carer.

Exclusion criteria were those patients who are not normally resident at home and patients who do not have a family carer as their main care provider.

The patient population that participated in the project were varied. Eighteen patients were interviewed, (11 female, 7 male). Their profiles are shown below (Figure 2). The majority of patients were in the 75-84 age category. Fifty five percent lived with a partner, 28% lived alone, 11% lived within a family and 5.5% lived with a son or daughter.

| | |
|----------------------------|---|
| Gender | Female (61%, n= 11) Males (39%, n=7) |
| Age | 45-54yrs (11%, n=2) 55-64yrs (11%, n=2) 65-74yrs (22%, n=4) 75-84yrs (56%, n=10) |
| Living arrangements | Lives alone (28%, n=5) Lives with partner (55.5%, n=10) Lives with family (11%, n=2) Lives with son/daughter (5.5%, n=1) |
| Co morbidities | Y (33.3%, n=6) N (66.6%, n=12) |

Figure 2: Demographic profile of the patients interviewed (18)

The patients selected by the nurses working in the community varied in disease profile. Although cancer was the most frequent disease reported (n=6), the tool was also used with a wide variety of patients living with other chronic life-limiting conditions (Figure 3).

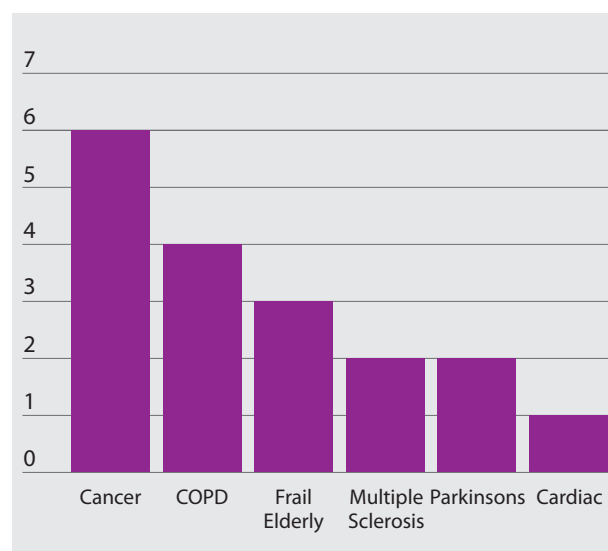


Figure 3: Disease profile of the 18 patients interviewed

² Voices4Care is an all-Ireland initiative involving people receiving palliative care (service users), carers and citizens with an interest in the work of AllHPC.

Phase 4: Evaluation

Methodology

The overall evaluation of the project was informed by a “realistic evaluation” approach (Pawson and Tilley, 1997), which sought to answer the question not simply “What works?” but “What works for whom in what circumstances?” This approach is recommended where the causative link between an intervention and its outcomes is multi-factorial. This approach recognised the need to evaluate not just outcomes, but also the processes leading to those outcomes. Therefore the overall approach for the evaluation was both formative, concerned with process, and summative, concerned with outcomes. The overall aim of the evaluation phase of the project was to assess the implementation of the DCI-Ireland tool with particular emphasis on the impact of the tool on patient care.

This involved:

- Identifying and exploring the patients/carers experience of using the tool.
- Identifying the barriers and facilitators to implementation of the tool.
- Identifying and exploring the impact of training on the nurses
- Determine whether or not the intervention helped the patients for whom it was developed.
- Making recommendations for future roll-out of the DCI-Ireland tool

A mixed methods approach was adopted, comprised of various strands of work for each of the work packages.

- This was comprised of 4 stages:
- An analysis of the completed DCI-Ireland tool (n=25)
- Face-to-face interviews with the patient/carer dyads or an individual patient (n=18)
- Focus group interviews with the nurses in the pilot sites (4 focus groups- n=24)
- A follow up online questionnaire with PHNs and RGNs (n=27)

Stage 1: Analysis of completed DCI-Ireland Tool

In total 27 people completed the tool. Of these eighteen patients completed the tool and were interviewed. Reasons for not being available for interview included: death; (n=2) admitted into hospice care (n=2), declined to be interviewed (n=3), tool returned with no accompanying details (n=1) and not available for interview (n=1). The nurses approached a selected number of patients on their client list and having explained the project to them, asked for their written consent to implement the tool. Selection methods varied throughout the sites. In two of the sites the ADPHN met with the staff to examine the caseload and select potential patients already in the service for whom the tool might be suitable. Consequently, these patients were already known to the services. Each PHN or RGN was asked to recruit one patient. The other two sites delegated the selection and use of the tool to the nursing staff. Similar to the previous two sites the patients were already in the services. Before implementing the tool each patient was asked if they were willing to participate in the project and were required to complete a consent form if they agreed. Additionally, they were asked if they would agree to be interviewed by a third party about the process of using the tool.

The completed forms were collected by the nurses and returned to the project team who followed up with the patients.

The tool consists of 26 questions each ranked from 1-5, with one being ‘not a problem’ and 5 being ‘an overwhelming problem’. The patients self-reported the perception of whether or not any of the 26 statements were a problem. This was graded on a 1-5 scale, ranging from one not being a problem to five being an overwhelming problem

Once the tool was completed by the patient and the nurse, the consent form was returned to the project manager along with the patient or carers phone number. This allowed the project manager to contact the patient/carer to set up a suitable date and time for interview. All of the interviews took place in the patients’ own homes. In some cases their family carer was present, however the choice of whether the carer was present or not was made by the patient. In all but one case the patients agreed for the interview to be taped (Notes were taken in the one untapped interview). Each interview was paced to suit the patient and varied in length from 25 to 55 minutes. The interview explored the patients’ perceptions regarding the relevance and usefulness of the tool and whether it enabled their dignity-related concerns to be met.

Twenty five completed tools were returned and analysed. Of these 25 returned tools, 16 were from patients who were subsequently interviewed and the remainder were from patients who were not interviewed. Although no completed tool was received for either patient 1 or patient 4 they were interviewed. Another patient completed the tool but they omitted to answer questions 15 -20 of the tool.

The 25 completed and returned tools were analysed to;

- Explore the clarity and ease of the tool for the patient.
- Discover if any particular problem was a particularly prevalent problem among the patient group.

Replies to the 26 questions showed that 49.92% of answers recorded by patients on the tool were in the category of 'no problem' (Figure 4). Findings from each of the categories illness related concerns, dignity conserving repertoire and social dignity inventory are presented below.

Illness Related Concerns

Among all eight questions (1-8) on the Illness Related Concerns category, 35% (n=69 responses) were rated to be not problematic. Almost 20% of replies to the questions fall into the moderate category while 6.52% of answers fell into the major or overwhelming problem category. The one exception was question 1, which related to pain and for which the response were most often rated three or above. Nine of the 25 patients (36%) scored the pain question (experiencing distressing symptoms such as pain, shortness of breath, nausea) as a major or overwhelming problem.

Dignity Conserving Repertoire

The Dignity Conserving Repertoire (questions 9-20), demonstrated a higher score in the lower end of the problem severity scale (75.69%). 5.2% of patients reported severe or major problems in this category. Question 16, 'feeling I don't have control over my life' received the highest ranking of the questions in this category with 3 people scoring this as a severe to overwhelming problem. Thirteen patients reporting this same level of problem with question 19, 'not being able to continue with my usual routines'. There is a strong link between these two questions so it is no surprise to see them ranked higher than other problems.

Social Dignity Inventory

Social dignity was addressed in the last six questions (20-26). The majority 85.41% of patients report no problem or a slight problem in this area. Twenty people (80%) stated that they had no concern about their spirituality, while the other 4 (15%) considered it to be a problem but not a major one.

| | Not a Problem | Slight problem | A problem | Major problem | Overwhelming problem |
|--------------|---------------|----------------|-----------|---------------|----------------------|
| Total number | 314 | 161 | 113 | 33 | 8 |
| Total % | 49.92% | 25.60% | 17.97% | 5.25% | 1.27% |

Figure 4: Ranking of patients perceptions of all 26 problems on the DCI-Ireland Tool.

Summary of the DCI-Ireland Tool

Overall, almost 50% of the 25 statements from DCI-Ireland tool were deemed not to be a problem for patients. However, one question was singled out by the nurses in the interview. This question addressed 'how illness or death would affect family or friends'. This question was answered by all patients and was not a serious issue for the majority (n=23).

Although the nurses also mentioned that they felt the questionnaire was too long, this did not appear to be problematic for patients possibly because the tool was left with them for approximately a week and they could fill it in whenever they wished.

KEY POINT:

Most patients scored low on the severity of problems

Stage 2: Individual patient/carer interview

Data Analysis

The interview data from both the patient interviews and the focus group interviews with the nurses was analysed using Burnard's step by step process of coding semi-structured interviews (Burnard 1991). The underlying strength of this method is the presentation of quotations from the interviews to support the analysis. This information was verified by the responses from the electronic survey of the participating nurses. Data saturation was reached within the interviews with no new information emerging in the last three interviews.

The overall findings from the patient/carer interviews on the use of the Dignity Care Intervention-Ireland Tool are presented under the following themes: Perceptions of dignity and Patient perceptions of the DCI-Ireland tool.

Patients perceptions of dignity

Dignity as a concept can be interpreted differently depending on the person, situation and many other factors. Dignity is important for people who have a long term illness or a life threatening illness that interferes with their capacity to do everyday tasks for themselves. Patients were asked in the interviews for a personal definition of dignity.

One male participant articulated dignity as,

"I suppose not been perceived by others as being foolish or ignorant, in other words held in reasonable regard by other people and by having a bit of privacy as well. The basic respect from other people (Pt Int 18).

In many cases patients discussed dignity in relation to specific tasks, events/issues – toileting, dressing and to the attitudes of others. It was as much about having a choice in how to do essential elements of living, "you want to do things ... yourself and not have then imposed on you" (Pt Int 13). Dignity was seen as problematic "when you have to get other people to do things for you" (Pt Int 16). All the people interviewed had been diagnosed with their illness for at least six months and had experienced a revision of their abilities to self-care, especially as they now needed input from both health professionals and others to maintain their everyday lifestyle.

Those who had an illness that made it more likely that they would become dependent in the near future were anxious about what this would be like and how it would affect control over their body and the effect it could have on their family.

These concerns frequently centred round personal care tasks such as toileting. One person who was wheelchair bound for many years felt their dignity was compromised but they had to put this aside and built a new norm around hygiene tasks:

"The first time that I had to get help to go to the toilet I thought it was the most awful thing in the world that I couldn't use my hands. I thought that was unbelievably bad. It was just crushing. But then I said, well I have to get help otherwise I won't survive. So that is the way it is. ... You just have to put it away. It has to be done" (PT Int 5).

It appeared that when people took some control over the management of the tasks at hand they felt better equipped to maintain their dignity. One patient reported,

"My daughter used to come in and wash my back for me and she said, I won't be looking. But I said I would just go in, get stripped and I'll sit with my back to you (Pt Int 1).

Many of the patients felt strongly about having outsiders coming into their homes to assist them to carry on 'normal' activities of living. This lady coped by making sure she was out of bed when the care attendant came to wash her, despite the fact that it could take a good deal of time and effort to do so. The ability to have some control over their care however small was the key factor in maintaining dignity.

"I am a very private person in myself... (Before) I'd get into my car and I'd like to be able to go to do the shopping and I'd love to go off and get my hair done and the clothes and all that but I find this thing (having someone come in to assist her in washing) absolutely dreadful" (Pt Int 6).

KEY POINT:

The ability to have some control over their care however small was the key factor in maintaining dignity

Having to take help from other people altered the way patients saw themselves. One carer when talking about her husband's life and the dignity issues for him and she summed it up thus, "(his) whole life area has shrunk, it has shrunk usually to a room or a bed or to a house" (Pt Int 18). This coupled with a dependence on carers and family narrowed the man's social contacts and left him dependant on others for the activities of daily living. By building a new method of viewing their situation patients began to adapt. Dignity could be summed up as adapting to a new situation and learning to cope with it.

The majority of patients and their carers spoke of the importance of the approach of professionals within the health care services. This entailed being listened to and being treated as an individual. With one male patient having a man to wash him made a great difference to his life. As his wife who is his main carer remarked about her husband,

"Dignity wise, it is much better for him to have a man rather than to say a woman. You know, he (the care attendant) lets Bert do as much as he can himself and would make sure that bits don't get missed. ... And at the end he gives him a nice shave." (Pt Int 18).

A key issue for patient who completed the DCI-Ireland tool appeared to be the physical dimensions of care which although most mentioned areas in the recount of patient stories about dignity were not identified as being overly problematic in the completed tool.

KEY POINT:

Challenges to dignity were overcome through a combination of matching patients and paid carers as well as having someone to call on should the need

Patient perceptions of the DCI- Ireland Tool

The method of introducing the tool to the patient varied across all areas. Depending on the time available and given the fact that the nurses already knew the patients, the distribution ranged from dropping the tool to a patient without much discussion. *"It was kind of a busy morning so I didn't really discuss it (the tool) with her"* (PT Int 12). In the majority of cases the nurse left the tool with the patient to complete following a discussion of the project and how to approach answering the questions in the tool. *"She left it (the tool) here with me one day and I filled it in myself"* (Pt Int 15). Indeed, this particular patient also reported that she did not have a chance to sit with the nurse and discuss the completed tool. But usually there was a discussion between the nurse and the patient about how to complete the tool and after completion there were discussions about any issues that arose. However, one patient remarked that the nurse; *"rang me up about it and asked me if I would take part in this thing... They just want to do this pilot thing and she explained it fairly well"* (Pt Int 13). In one instance the method of introduction the tool gave the patients the impression that this was a data gathering exercise rather than an assessment tool and in doing so reduced the potential to engage the patient in in-depth discussion about their care. This was evident from this patient's statement;

"She left it here with me and X (daughter) helped me fill it in. ... tool) I have had this problem for year and have been through all these things. So she collected it sometime later ... no we didn't talk about it and I really didn't have any problems" (Pt Int 5).

Patients were given time to complete the tool over a number of days and then were revisited by the nurse to review it. Overall, the patients found the tool self-explanatory and none of the patients reported any difficulty completing the tool. One person did remark that some questions were repeated *"they are nearly the same question (two of the questions) but asked in a different way"* (Pt Int 3). Patients themselves for the most part, completed the tool one or two instances the main carer completed the form in conjunction with the patient. These same two carers then led the interview referring to the patient for confirmation. As one patient/carer dyad remarked *"we went over it (together) and I must say that I did most of it because, just from my point of view (Patient's name)"* (Pt Int 18).

Stage 3: Focus group discussion with nurses

The overall findings from the focus group discussions on the use of the Dignity Care Intervention-Ireland Tool are presented under the following themes and subthemes:

- Nurses perceptions of dignity
- Use of the tool in practice
 - ‘Picking and choosing too carefully’
 - ‘Piece of paper to read and boxes to tick’
 - ‘Opening a can of worms’
- Benefits and challenges using the tool

Focus group interviews were conducted with a sample of all nurses involved in the project to assess usefulness of the tool and the potential for roll-out across nursing services regionally and nationally. These interviews took place at either the local health centre or the local HSE local office. The focus group interviews explored a) the nurses’ perceptions of the content and process of delivering the end of life dignity intervention; b) potential barriers to successful use of the DCI-Ireland tool to conserve dignity in end of life care and, if any, how these barriers could have been overcome; c) factors that facilitated the use of the framework; d) if the training was adequate preparation for the use of the tool or if adjustments need to be made depending on the context in which the tool is being implemented, were also discussed. This allowed each pilot site to discuss the process of using the tool as well as the challenges in using it. Two people conducted the focus groups with the nurses and the group size varied from 6 and ten people. The length of time for each focus group ranged from 44 to 60 minutes.

Nurses perceptions of dignity

The nurses who took part in the study identified their perceptions of dignity in relation to their patients. These included, *“Meeting the person where they are at”, “Respecting their wishes”, “Maintaining their wellbeing”, “Making sure they are comfortable and content with their own wellbeing”, “Involved in the decision making, it’s very important, it’s not someone making the call for them”* and *“looking at what their care needs are, rather than what I expect them to be”*.

What emerged from these descriptions was the need for an individualistic approach to patients which demonstrated their awareness of the need for respect. The nurses viewed dignity as respect for the person as an individual. Dignity was defined by the nurses as respect or as a need for recognition for the person whilst the patients tended to explain their concept of dignity through descriptions of actions that they felt demonstrated dignity.

Use of the tool in practice

This described the experience of the use of the DCI-Ireland tool by nurses in practice in the pilot sites. It also detailed the benefits and challenges posed by the introduction of this tool.

“Picking and choosing the people too carefully”

Following education on the use of the tool as outlined in Phase 3, the nurses were asked to pilot the tool in their work area. From the nurses’ perspective, they all without exception choose to use it on clients who were already in the service. While this was a practical approach for the selection of the clients it could be perceived as a method of ‘choosing appropriate patients’ as one nurse remarked, *“I knew (named patient) would be able to talk (FG Int 2). It also gave a perspective on how comfortable the nurse felt using the tool, “It would be easier to identify with people I had known a long time with a chronic illness” (FG1). Subsequently, the tool was distributed to patients already known to the nursing service for many cases for a number of years. It could be suggested that this limited his limited the potential benefit of the tool as much of the required care and resources were already in place. This was acknowledged by the nurses who saw the restrictions of such actions.*

“I felt that maybe one way, we were picking and choosing the people too carefully ... We were kind of being cautious about who we chose to do it.” (FG 4).

KEY POINT:

Patients already on the PHN caseload were ‘carefully’ selected for the project Approach to tool introduction and completion of the tool varied

The nurses identified how families sometimes acted as gatekeepers to the introduction of the DCI -Ireland tool. For example on one occasion it was noted that whilst a patient was willing to complete the tool, her husband got distressed over it and she never got to use the tool. He asked,

“Why would you be asking questions – is she supported by the family, of course she is supported by the family. ... She was fine with it and she was saying, that’s fine, we don’t have to fill it out, it doesn’t matter whether I answer it or don’t answer it. Whereas he was getting very worked up anyway it didn’t get done and it was more because of his outlook on it than hers” (FG 3).

In the end this couple did not complete the tool. In another instance the patient’s son was reluctant to allow any discussion of death with his mother. Meanwhile the nurse had been talking to the patient and she was scared of dying,

“She wanted to die in a Hospice and her son would not let her. He was scared of letting her go into a hospice. We got a bed for her in the hospice because that was her wish but he refused to let her go” (FG 4).

KEY POINT:

In some cases the family acted as ‘gatekeepers’ to the introduction of the tool

“Piece of paper to read and tick boxes”

While the patients reported no problems with the tool, it was considered challenging by some of the nurses due to its length (26 items). One of the nurses interviewed reported that they took the patients through the tool as opposed to leaving it with them as was advised. In this case it became a time consuming exercise:

“... because when they are reading it on front of you they are not as relaxed as they would be if they were reading it themselves” (FG1).

I was also suggested that not all of the questions needed to be dealt with at the first return visit after the tool had been administered, rather that the important issues were dealt with immediately and then the nurse could deal with the other issues on

subsequent visits.

In one case the nurse reported she spent three hours talking to the patient about issues that arose for the patient when completing the form (FG 3).

During the course of the focus groups a number of nurses raised the issue of a heavy caseload as a reason for not implementing the tool

KEY POINT:

Some nurses considered the tool too lengthy to use regularly in practice.

Heavy caseloads and lack of manpower were cited as reasons for not introducing the tool.

Certain reservations were expressed mainly about who would be suitable candidates for its use. For some reason ticking the boxes seemed to be problematic *“the patient ticking the boxes with some clients wouldn’t be appropriate” (FG 1).*

Other nurses had problems with leaving the tool with some clients. It was suggested that if the nurse could decide to choose between leaving the tool with the patient or alternately taking the patient through the tool, then the tool would be more versatile and had a better chance of being used.

KEY POINT:

There is a fear that this tool could become a matter of ticking boxes

“Opening a Can of Worms”

Having used the tool on existing patients the nurses were asked if they had gleaned any new information that would assist them in their care of their patient. Overall, nurses reported that little new information emerged from the patients (FG 3, FG4). Considering many of them had been long term patients on PHN’s caseload, this was no surprise. Many of the nurses had ongoing contact with the clients because

of leg ulcer care or some continual problem that required constant attention. However, one nurse did remark that she had gained a new perspective on an existing client and that as a result of using the tool, her patient had altered her thinking about the status of her health and her future accommodation needs (FG3). The nurses also mentioned that people may have slowly considered and reflected on the questions started asking questions some weeks after the tool was employed. For example during one of the Focus Group interviews a nurse commented

"I started thinking that must have something to do with the tool. ... one of them went on about going to the solicitor, the land, they are a couple with no children and a bit of farm land" (FG3).

KEY POINT:

The tool supplied an opportunity to gain new perspectives on patient's issues

However, the idea of patients asking questions around the areas covered by the tool raised some difficulties for the nurses. They felt that once the questions were asked there was an onus to follow through any issues that arose. They stressed that it might generate more visits but

"Once you open that can of worms ... you do have to go back, you cannot leave the person hanging with these ideas and they are unfinished. It takes a lot of time". (FG2).

This notion of the can of worms arose on several occasions with the nurses. One nurse reported that when using the tool on a patient who had lost her long-term partner a year earlier, it seemed to re-awaken the feeling and the person was upset. However, she also commented that there was a positive aspect to this as

"I do suppose it is good for them if they get passed the point where they might be a bit upset ... then they get some resolution" (FG 3).

What did emerge was this type of intervention took time that was previously not factored into the home visits. The time factor was important as the nurses perceived they already had an overwhelming workload and this was an added task with no added staff resources. As in-depth discussions took place

nurses were stretched in dealing with the issues surrounding death. Some of them felt they lacked the skills to talk about these issues. A few nurses also stated that "there will be the some questions that we won't be able to ask clients" (FG 4). Probes into this statement revealed that the nurse and some of her colleagues did not feel comfortable discussing issues around death and dying. While others suggested that the tool gave them an opportunity to raise issues that might not otherwise be raised due to time constraint or to a lack of confidence on the part of the nurse to discuss these issues.

KEY POINT:

Some of the nurses felt they lacked the skills to talk about death and dying

It does seem that the tool was considered helpful to introduce areas that could be potentially difficult to discuss. This was considered a good mechanism to get a person talking about sensitive areas or areas that might be missed as the nurse could not predict the patient's state of mind. It was remarked that the statements in it were blunt,

"But then blunt isn't the right word either. ... I like the directness of it because if you have a new palliative diagnosis ... I think the directness makes them think what is important, what they want done now, what they want in six months' time and what they wouldn't care if it was never done. ... (It) focuses them" (FG3).

As the following excerpt shows, the tool can highlight problems that might otherwise go undetected.

"I had one lady, ... she said she hadn't got the courage to do it and she used the word courage ... (it) made her question a bit more but she had always been a little depressed and her daughter got her reviewed again. She was depressed and some of these questions highlighted that" (FG 3).

As a result of using the tool this woman saw her GP and her medication was changed.

KEY POINT:

Problems that might otherwise have gone undetected were raised by this tool

Benefits and challenges of using the tool

There were various perceived benefits and challenges to using the tool in practice.

Benefits

Whilst there were concerns raised from the focus group discussions there was a general endorsement of the tool from many of the nurses who used the tool. The nurses found that the tool could open up a discussion about the future need of a patient. For one woman who had complex problems and who previously had avoided talking about them, the tool allowed her to start verbalising her thoughts and fears. The nurse reflected that filling in the tool appeared to help the patient.

"(It) gave her a bit of insight, it made her think about her situation and I think it helped her, it stimulated her to think (FG 3 2

The result was that this point that this patient began to give some thought to her future and how she could manage at home.

Another benefit of the tool was that the nurses considered the tool to have helped to make explicit the work that they do and provided some assistance for their overall assessment:

"It's putting into words what we do (FG 4) and

"I think a lot of this stuff you do on a visit without even thinking about it" (FG1).

"It's a great opener for nurses" (FG 4).

In all the nurses who were less confident about talking about death and dying were enthusiastic about this tool "I found it a very positive thing because I'm not good about talking about end of life" (FG4). While the majority of the nurses were enthusiastic about using the tool they did have reservations, related to time and lack of skills.

"Oh yeah, if you had time. [All agreed] There is an awful lot of time involved if it's someone you know very well or that you have been attending to for years. ... I think to use it properly you would need an awful lot of time" (FG3).

KEY POINT:

Nurses saw this tool as a way of measuring what they already do.

The time taken to complete all stages of the tool administration was problematic.

Challenges

Whilst this tool was intended to be used as an assessment for maintaining dignity, the nurses felt that it would be difficult to use this at the initial interview. Rather, they considered that it was important establish a relationship prior to using the tool in practice:

"You feel you have to establish some sort of relationship before you go in and ask him would he mind doing it" (FG1).

As in-depth discussions took place nurses were stretched in dealing with the issues surrounding death. Some of them felt they lacked the skills to talk about these issues and this then raised concerns about the referral services to other health care professionals such as psychologists and the specialist palliative teams. Whilst some of the nurses felt comfortable discussing death and related issues with their patients stating that it was part of their role, "I think a lot of this stuff you do on a visit without even thinking about it" (FG1), others were less equipped. This was reflected to be an overall cultural factor related to an overall reluctance to engage with discussions on death and dying.

"I think it is a cultural thing. Death and dying and talking about it, certainly during my training it was not something that was discussed. A lot of people were not even told their diagnosis" (FG1).

As a result many of the nurses avoided this issue. Some of them felt the tool was inappropriate as it was based on a tick box schema that was intended to be a starting point for an open discussion and not an end in itself. However, one or two nurses seemed to be unaware of this and remarked "I was going to give her a piece of paper to read and tick boxes and I felt it was not us as nurses" (FG 4). This particular was not alone in interpreting this tool as an end rather than a starting point in the Palliative care process. She remarked

"There are people in a really sad time of their life and you are giving them a questionnaire where somebody was going to phone back and ask them questions about that questionnaire. I just didn't like it" (FG 4).

This focus on the project rather than the use of the tool as a dignity conserving tool was manifest throughout the project. The method used by some of the managers to implement the tool by selecting 'suitable clients' interfered with the process of seeing the tool as a normal data collection/assessment tool for patient care.

Certain reservations were expressed mainly about who would be suitable candidates for its use. For some reason ticking the boxes seemed to be problematic “the patient ticking the boxes with some clients wouldn’t be appropriate” (FG 1). Other nurses had problems with leaving the tool with some clients. It was suggested that if the nurse could decide to choose between leaving the tool with the patient or alternatively talking the patient through the tool, then the tool would be more versatile and had a better chance of being used.

Stage 4: On Line Survey

Following the focus group interviews with the nurses an online survey was conducted for all the nurses in all the pilot sites. The aim of this survey was to collect data to assist in the verification of the information obtained from the focus group interviews and to attempt to capture material that might not have emerged from these interviews. Twenty seven nurses of the 88 nurses recruited to answer the questionnaire responded. This represented 30.4% response rate (Figure 5).

| | |
|-----------------------------------|---|
| Gender | Female (100%, n=27) |
| Age | 25-34yrs (4%, n=1) 35-44yrs (32%, n=8) 45-54yrs (36%, n=9) 55-65yrs (28%, n=7) |
| Current area of practice | Public Health Nurse (73%, n=16) Community RGN (27%, n=6) |
| Length of time working as a nurse | 6-10yrs (8%, n=2) 11-15yrs (12%, n=3) 16-20yrs (16%, n=4) 20+yrs (64%, n=16) |
| Working arrangements | Full-time (68%, n=17) Part-time (24%, n=6) Other (8%, n=2) |
| Educational qualifications | Certificate (42%, n=11) Diploma (38%, n=10) Degree (35%, n=9) Masters (19%, n=5) |

Figure 5: Demographic Profile of survey respondents (n=27)

The majority of respondents (96%, n=26) attended the education sessions on the DCI-Ireland tool which were delivered either face-to-face, online or both. Interestingly, nearly 60% (n=16) of respondents who completed the survey had previously participated in palliative care-related study days and/or courses. When asked if they had used the DCI-Ireland tool in their practice, 67% (n=18) of respondents reported that they had with 75% (n=12) of these having used it with an existing patient. Figure 8 identifies the length of time respondents (n=16) knew their patient before administering the DCI-Ireland tool.

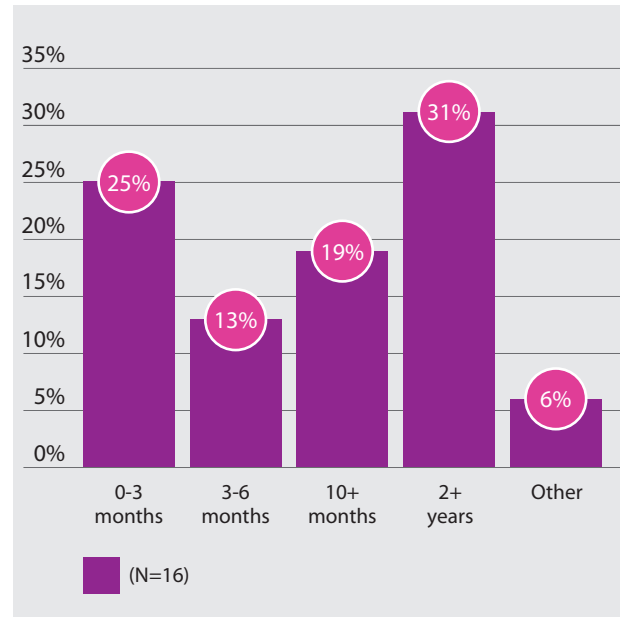


Figure 6: Length of time respondents knew their patient before administering the DCI-Ireland tool

Of the 33% (n=9) of respondents who did not implement the DCI-Ireland tool with their patient(s), 38% (n=5) of these indicated that their patient had died, 23% (n=3) indicated that the patient was admitted to hospital, and a further 38% (n=5) indicated ‘other’ without explanation. Interestingly, none of the respondents indicated that the patient or the patient’s family had objected to the DCI-Ireland tool being implemented with them.

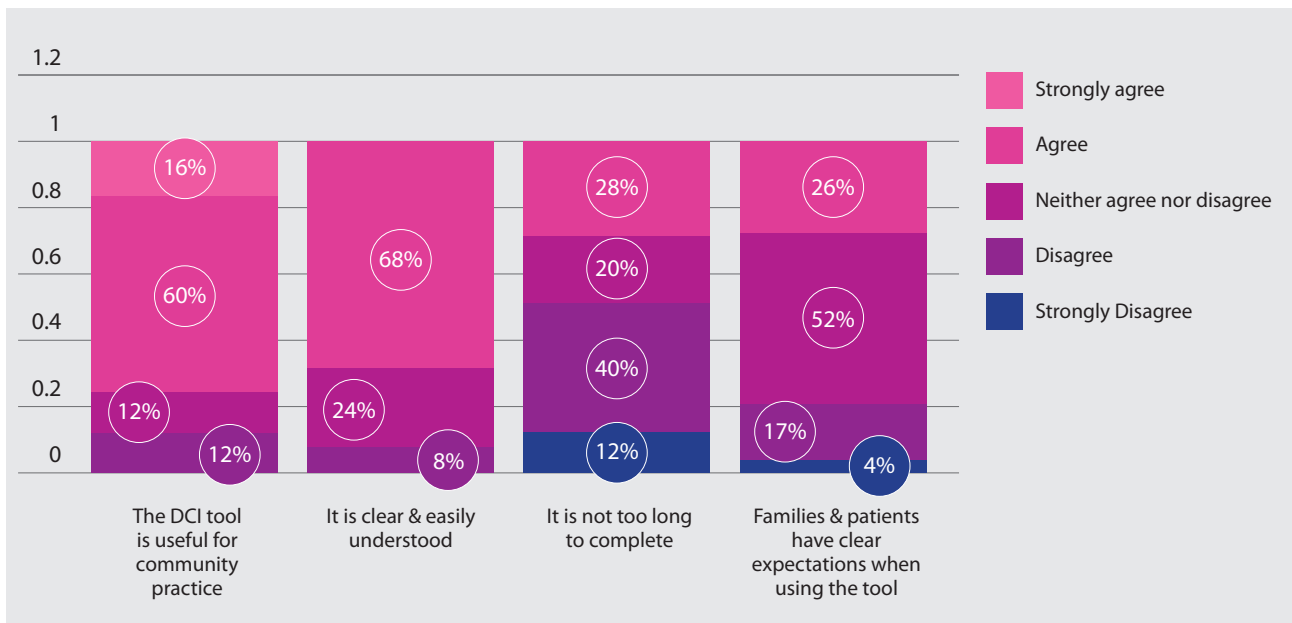


Figure 7: Perceptions of the DCI-Ireland tool

Respondents were invited to share their thoughts about the DCI-Ireland tool. 76% (n=19) of respondents agreed/strongly agreed that the DCI-Ireland tool is useful for community practice while 68% (n=17) agreed that it was clear and

easily understood (Figure 7). However, 52% (n=13) disagreed/strongly disagreed that the DCI-Ireland tool is not too long to complete. Figure 9 provides a further summary of those responses (N=25).

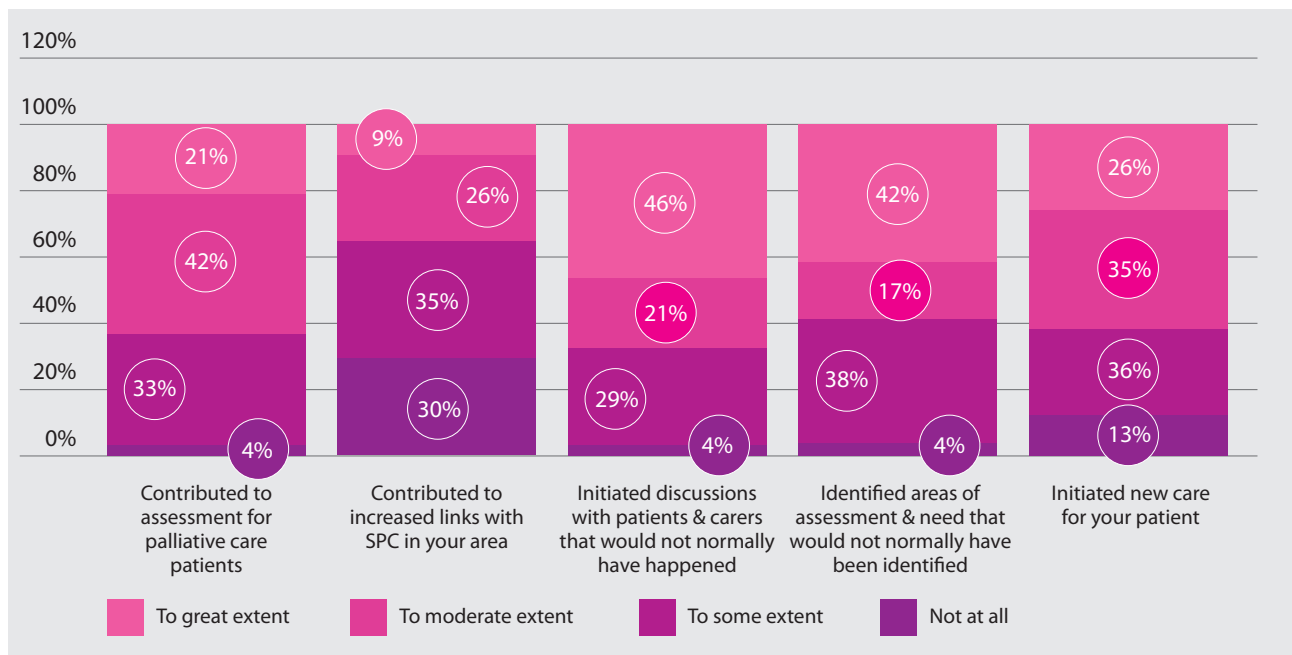


Figure 8: Contribution the DCI-Ireland tool made to various aspects of practice in a community setting

Respondents were asked to consider the potential contribution the DCI-Ireland tool made to various aspects of their practice in a community setting (Figure 8). 63% (n=15) of respondents reported to a great/moderate extent that the tool had contributed to the assessment for palliative care patients; 67% (n=16) reported to a great/moderate extent that the tool had initiated discussions with patients and carers that would not normally have happened; 59% (n=14)

highlighted to a great/moderate extent that the tool had identified areas of assessment and need that would not normally have been identified; and finally 61% (n=14) reported to a great/moderate extent that the tool initiated new care for their patient. In contrast, 65% (n=15) of respondents believed that the tool had not at all/to some extent contributed to increased links with SPC in their community.

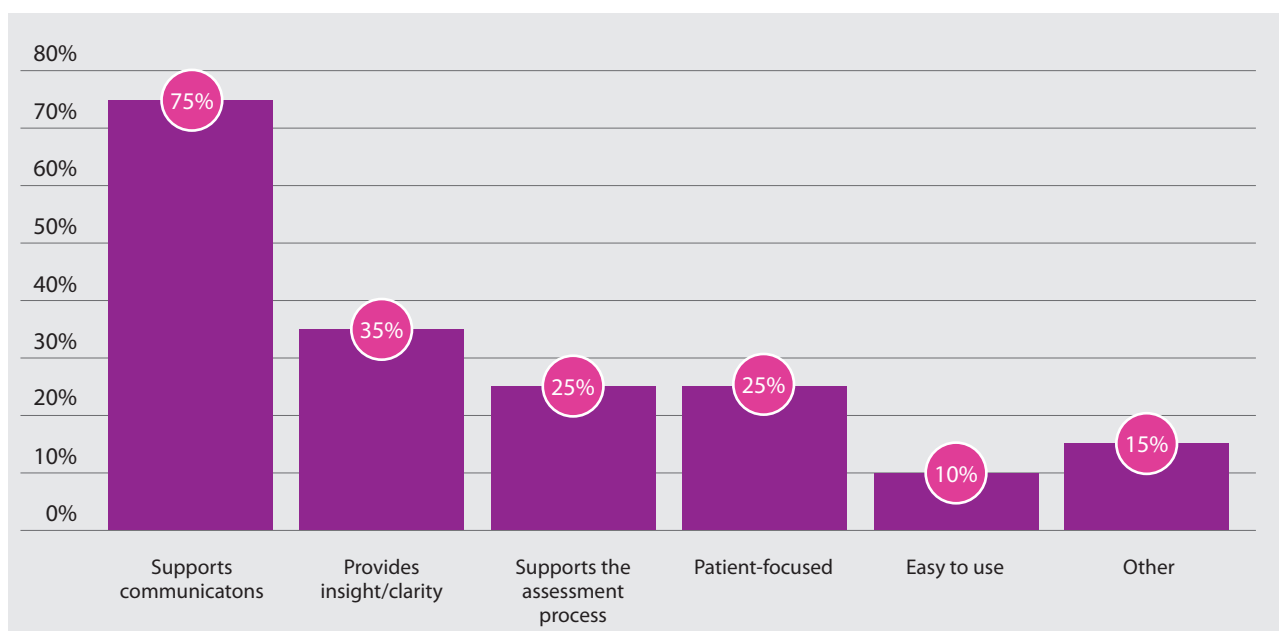


Figure 9: Best things about the DCI-Ireland tool as reported by respondents (nurses).

Respondents were invited to share their views regarding the three best things about the DCI-Ireland tool (Figure 9). Twenty individuals responded to this question with the majority of those (75%, n=15) reporting that the tool supported communication (e.g. enabling sensitive conversations, allowing people to talk, creating an

openness about death and dying, etc.). 35% (n=7) of respondents indicated that the tool helped them to gain an insight or greater clarity into the needs and experiences of the patient. 25% (n=5) stated that the tool supported the assessment process while a similar proportion of respondents indicated that the tool was patient-focused.

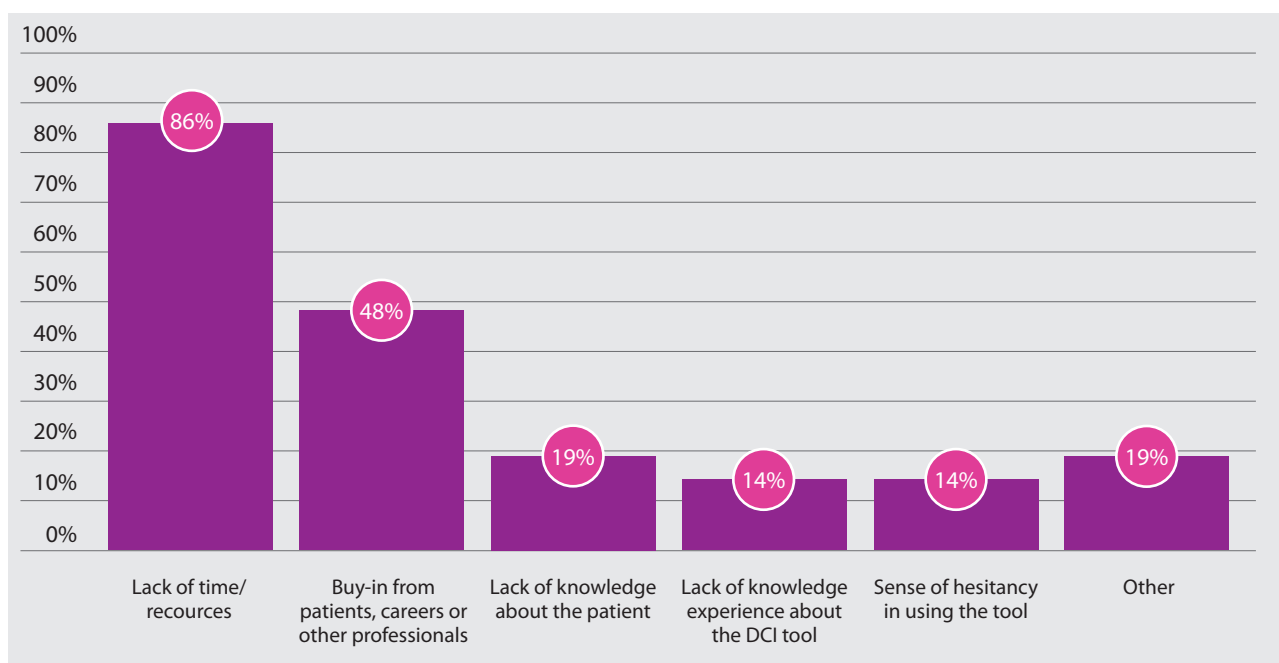


Figure 10: The biggest challenges to using the DCI-Ireland tool in practice

Of the 21 responses to the question “what are the biggest challenges to using the DCI-Ireland tool in practice”, 86% (n=18) of respondents reported that a lack of time and/or resources were the biggest challenges. 48% (n=10) of respondents indicated that getting buy-in from patients, carers

or colleagues was a further challenge. Interestingly, 19% (n=4) stated that another challenge might be having a lack of knowledge of the patient. A summary of responses to this question are presented in Figure 10.

Final 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.

Limitations

- The patients interviewed for the project were all previously under the care of community services prior to being given the DCI-Ireland tool to complete. This limited the ability of the assessment to pick up previously unaddressed areas in need of attention. Services such as assistance with hygiene needs had already been addressed and put in place. Even if these were less than ideal it is more difficult to change an existing service than to implement a new one to match the patient's individual dignity need.
- Many of the community nurses, including some of the dignity champions moved clinical base within the services during the lifespan of the project. Consequently, the momentum of the project was delayed while new staff were identified and introduced into the project.
- Community nurses needed ongoing engagement from the Project Manager to identify and select the patients for the project. This required multiple visits to the relevant Health Centres to re-orientate the nurses to the project.
- The community nurses saw the introduction of the DCI-Ireland tool as an added workload and one health centre opted out of the project citing workload issues. This had the effect of reducing the number of patients introduced to the DCI-Ireland tool.
- There was a change in the project manager and a gap of two months between one person leaving and the new person taking up the role. This occurred during the time that the tool was being implemented by the community nurses. Consequently, there was a delay in moving the project forward.

Dissemination Activities

Dissemination and knowledge transfer activities in Phase 1 and 2 of the project include the following:

- Presentation at the Institute of Community Health Nursing Annual General Meeting (AGM) 23rd November 2013, Milltown Institute, Ranelagh, Dublin
- Conference Presentation- 'Living and Dying Well in the Community: The Future of Primary Palliative Care in Ireland' 15th May 2014, Ashling Hotel, Dublin
- Dignity Care Intervention Project Presentation to President Michael D. Higgins (President of Ireland) at the Institute of Community Health Nursing Annual Conference 21st May 2014, Milltown Institute, Ranelagh, Dublin

Publications Arising from the Project

Peer reviewed publication:

Johnston B, Larkin P, Connolly M, Barry C, Narayanasamy M, Ostlund U, and McIlpatrick S. (2015) Dignity-conserving care in palliative care settings: An integrative review. *Journal of Clinical Nursing, Early View*.

Poster Presentations

Connolly M, Barry C, Charnley K, Philip P, McIlpatrick S, Johnston B (2015) *Dignity Care Intervention Ireland (DCI-Ireland): Education Evaluation for Nurses Working in the Community Setting*. Building Bridges 14th World Congress of the European Association for Palliative Care. May 8-10th Copenhagen.

McIlpatrick SJ, Larkin P, Connolly M, Johnston B (2015) *Implementing a Dignity Care Intervention for people with life limiting conditions in a community setting in Ireland*. Building Bridges, 14th World Congress of the European Association for Palliative Care. May 8-10th Copenhagen.

Oral Presentation

McIlpatrick SJ, Larkin P, Connolly M, Collins R, Johnston B (2015) *Implementing a Dignity Care Intervention in Ireland*. Kaleidoscope Conference. Palliative Care Beyond Cancer: The Journey Towards Inclusiveness, 14th Annual Kaleidoscope Palliative Care Conference May 13-14th, Dublin Castle

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Appendix 1: Patient Dignity Inventory (PDI)

Illness Related Concerns

| | | | | |
|---|------------------|-----------|-----------------|-------------------------|
| 1. Experiencing physically distressing symptoms (such as pain, shortness of breath, nausea) | | | | |
| 1 | 2 | 3 | 4 | 5 |
| Not a problem | A slight problem | A problem | A major problem | An overwhelming problem |
| 2. Feeling depressed | | | | |
| 1 | 2 | 3 | 4 | 5 |
| Not a problem | A slight problem | A problem | A major problem | An overwhelming problem |
| 3. Feeling anxious | | | | |
| 1 | 2 | 3 | 4 | 5 |
| Not a problem | A slight problem | A problem | A major problem | An overwhelming problem |
| 4. Feeling uncertain about my health | | | | |
| 1 | 2 | 3 | 4 | 5 |
| Not a problem | A slight problem | A problem | A major problem | An overwhelming problem |
| 5. Worrying about my future | | | | |
| 1 | 2 | 3 | 4 | 5 |
| Not a problem | A slight problem | A problem | A major problem | An overwhelming problem |
| 6. Not being able to carry out tasks associated with daily living (e.g. washing, getting dressed) | | | | |
| 1 | 2 | 3 | 4 | 5 |
| Not a problem | A slight problem | A problem | A major problem | An overwhelming problem |
| 7. Not being able to attend to bodily functions independently (e.g. needing assistance with toilet related activities) | | | | |
| 1 | 2 | 3 | 4 | 5 |
| Not a problem | A slight problem | A problem | A major problem | An overwhelming problem |
| 8. Not being able to think clearly | | | | |
| 1 | 2 | 3 | 4 | 5 |
| Not a problem | A slight problem | A problem | A major problem | An overwhelming problem |

Dignity-Conserving Repertoire

| 9. Feeling that how I look to others has changed significantly | | | | |
|--|------------------|-----------|-----------------|-------------------------|
| 1 | 2 | 3 | 4 | 5 |
| Not a problem | A slight problem | A problem | A major problem | An overwhelming problem |
| 10. Feeling like I am no longer who I was | | | | |
| 1 | 2 | 3 | 4 | 5 |
| Not a problem | A slight problem | A problem | A major problem | An overwhelming problem |
| 11. Not feeling worthwhile or valued | | | | |
| 1 | 2 | 3 | 4 | 5 |
| Not a problem | A slight problem | A problem | A major problem | An overwhelming problem |
| 12. Not being able to carry out important roles | | | | |
| 1 | 2 | 3 | 4 | 5 |
| Not a problem | A slight problem | A problem | A major problem | An overwhelming problem |
| 13. Feeling that life no longer has meaning or purpose | | | | |
| 1 | 2 | 3 | 4 | 5 |
| Not a problem | A slight problem | A problem | A major problem | An overwhelming problem |
| 14. Feeling that I have not made a meaningful and/or lasting contribution in my life | | | | |
| 1 | 2 | 3 | 4 | 5 |
| Not a problem | A slight problem | A problem | A major problem | An overwhelming problem |
| 15. Feeling that I have unfinished business | | | | |
| 1 | 2 | 3 | 4 | 5 |
| Not a problem | A slight problem | A problem | A major problem | An overwhelming problem |
| 16. Feeling that I don't have control over my life | | | | |
| 1 | 2 | 3 | 4 | 5 |
| Not a problem | A slight problem | A problem | A major problem | An overwhelming problem |
| 17. Not being able to accept the way things are | | | | |
| 1 | 2 | 3 | 4 | 5 |
| Not a problem | A slight problem | A problem | A major problem | An overwhelming problem |
| 18. Feeling like I am no longer able to mentally cope with challenges to my health | | | | |
| 1 | 2 | 3 | 4 | 5 |
| Not a problem | A slight problem | A problem | A major problem | An overwhelming problem |
| 19. Not being able to continue with my usual routines | | | | |
| 1 | 2 | 3 | 4 | 5 |
| Not a problem | A slight problem | A problem | A major problem | An overwhelming problem |
| 20. Concern that my spiritual life is not meaningful | | | | |
| 1 | 2 | 3 | 4 | 5 |
| Not a problem | A slight problem | A problem | A major problem | An overwhelming problem |

Social Dignity Inventory

| 21. Feeling that care needs have reduced my privacy | | | | |
|--|------------------|-----------|-----------------|-------------------------|
| 1 | 2 | 3 | 4 | 5 |
| Not a problem | A slight problem | A problem | A major problem | An overwhelming problem |
| 22. Not feeling supported by my community of friends and family | | | | |
| 1 | 2 | 3 | 4 | 5 |
| Not a problem | A slight problem | A problem | A major problem | An overwhelming problem |
| 23. Not feeling supported by my health care providers | | | | |
| 1 | 2 | 3 | 4 | 5 |
| Not a problem | A slight problem | A problem | A major problem | An overwhelming problem |
| 24. Not being treated with respect or understanding by others | | | | |
| 1 | 2 | 3 | 4 | 5 |
| Not a problem | A slight problem | A problem | A major problem | An overwhelming problem |
| 25. Feeling that I am a burden to others | | | | |
| 1 | 2 | 3 | 4 | 5 |
| Not a problem | A slight problem | A problem | A major problem | An overwhelming problem |
| 26. Worries about how illness or death will affect my family or friends | | | | |
| 1 | 2 | 3 | 4 | 5 |
| Not a problem | A slight problem | A problem | A major problem | An overwhelming problem |

Appendix 2: Steering Committee Dignity Care Intervention Project

| | | |
|--------------------|--|----------------|
| Barry Catriona | Programme Manage AIIHPC | Until Aug 2015 |
| Bourke Joan | Director Public Health Nursing, Dublin South City | |
| Collins Rita | Programme Manager 2015 | From Oct 2015 |
| Connolly Michael | Head of Education AIIHPC | |
| Corcoran Michael | CNM3, Specialist Palliative Care, Hospice at Home, Nursing Team, Milford Care Centre | |
| Donnolly Catherine | Clinical Nurse Manager, Our Lady's Hospice, Harold's Cross & Care services | |
| Donohue Ann | Programme Co-ordinator of the Graduate Diploma in Public Health Nursing, UCD | |
| Ferns Mary | Night Nursing Manager, Irish Cancer Society | |
| Hanley Catherine | Assistant Director of Public Health Nursing, ISA Dublin South Central | |
| Harris Anne | Project Manager, HSE National Advocacy Unit | |
| Johnson Bridget | Professor of Palliative and Supportive Care, Nottingham University, UK | |
| Kelly Joan | Nursing Services Manager, Irish Cancer Society | |
| Keogh Aidan | Assistant Director of Public Health Nursing Limerick | From Feb 2015 |
| Larkin Philip | Principal Investigator, Professor of Clinical Nursing [Palliative Care] OLH/UCD | |
| Lynch Marie | Programme Development Manager, The Irish Hospice Foundation | |
| Lynott Anne | | |
| McHugh Frances | DPHN ISA Dublin South Central | |
| McIlpatrick Sonja | Principal Investigator, Head of Research AIIHPC, | |
| Mc Keon Mary | Assistant Director of Public Health Nursing, Dublin South City | |
| Megan Michelle | Acting Director of Public Health Nursing, Wicklow | |
| Murphy Tara | Project Manager Research, AIIHPC | |
| O Connell Helena | | |
| O Dwyer Mary | Assistant Director of Public Health Nursing Limerick | Until Jan 2015 |
| O Dowd Mary | Executive Director, ICHN | |
| Peelo Kilroe Lorna | Nursing Lead for the Palliative Care Programme, ONMSD, HSE | |
| Shanaher Deirdre | | |
| Smyth Maeve | Assistant Director of Public Health Nursing, Wicklow | From Feb 2014 |
| Whitty Catherine | Assistant Director of Public Health Nursing, Wicklow | Until Jan 2015 |

Appendix 3: Expert Advisory Panel

Education:

Prof. Catriona Kennedy, University of Limerick

Dr. Ulrika Ostlund, Sweden

Clinical Practice:

Ann Tan, CNM 3 Team Leader Specialist Palliative Care, Laois & Offaly.

Practice Development:

Neil Dunne, Advanced Nurse Practitioner Community Older Adults

Ger Treacy ANP Palliative Care

Management:

Marianne Healy to nominate representative from DPHN group

Appendix 4: 'Train the Trainer' Programme

Dignity Care Intervention Ireland

| | |
|---------------------|--|
| | Morning Programme |
| 10:00 am – 10.05 am | Welcome by Catriona Barry, DCI-IRELAND Project Manager Introductions |
| 10:05 am – 10.30 am | Opening Comments, Lorna Peelo-Kilroe, Nursing Lead, HSE National Clinical Programme for Palliative Care / Office of the Nursing and Midwifery Services Director (ONMSD),HSE Background Information, Dignity Care Intervention Ireland Project, Catriona Barry Role of the Dignity Care Champion and DCI-IRELAND Education Co-Facilitator Dr. Michael Connolly, Head of Education AIIHPC |
| 10:30am – 10.45 am | Tea/Coffee |
| 10.45am-11.30am | Dr. Michael Connolly, Head of Education AIIHPC Review Principles of Palliative Care Principles of Communication skills in Palliative Care |
| 11.30am-12.30pm | Professor Bridget Johnston, Dignity Care Intervention Expert Advisor The Concept of Dignity Theory Underpinning Dignity Care Intervention Development of Dignity Care Pathway Scotland |
| 12.30 pm-13.15pm | Lunch Break |
| | Afternoon Programme |
| 13.15 pm-13.45pm | Professor Bridget Johnston, Dignity Care Intervention Expert Advisor Using the Dignity Care Intervention in Clinical Practice Training Manual Learning from DCP Project Scotland Issues re Implementing DCP in Scotland Frequently asked Questions |
| 13.45 pm-15.45pm | Dr. Michael Connolly, Head of Education AIIHPC DCI-IRELAND Case Studies Interactive Workshop, Skills Building |
| 15.45 pm-16.00pm | Questions |
| 16.00pm | Close |

Appendix 5: Education Co-Facilitators and Dignity Champions

Education Co-Facilitator, Dignity Care Intervention Project

| Name | Role | Area |
|------------------|----------------------------|----------------------|
| Emer Hough | Specialist Palliative Care | Milford Hospice |
| Helena O’Connell | PHN | HSE West |
| Catherine Whitty | ADPHN | Wicklow |
| Mary McKeon | ADPHN | Dublin South City |
| Irene Dunne | | Dublin South Central |
| | | |

Dignity Champion, Dignity Care Intervention Project

| Name | Role | Area |
|------------------|----------------------------------|----------------------|
| Martina Duffy | ADPHN | HSE Mid-West |
| Cathy Killeen | Irish Cancer Society Night Nurse | Irish Cancer Society |
| Yvonne Wall | Dublin South City | Dublin South City |
| Clare Keeley | | Wicklow |
| Aileen Carrig | Dublin South Central | Dublin South Central |
| Tracey Carey | CRGN | Wicklow |
| Nessa Fitzgerald | Specialist Palliative Care | OLH&CS |
| Mary O’Dwyer | ADPHN | HSE Mid-West |
| Isabel McMahon | PHN | Dublin South Central |
| Catherine Hanley | ADPHN | Dublin South Central |
| Mary Ferns | Night Nursing Manager | ICS |
| | | |

Additional names for Train the Trainer Dignity Care Intervention Project

| Name | Role | Area |
|-------------------|---------------------|------------------------------|
| Deirdre Shanagher | Development Officer | The Irish Hospice Foundation |

Appendix 6: Programme for Facilitated Workshops

**Dignity Care Intervention Ireland
Workshop Programme**

| | |
|---|---|
| Session 1 | |
| Facilitator – Catriona Barry, DCI-IRELAND Project Manager | |
| 5-10mins | Welcome and Introductions Pre-education questionnaire |
| 30mins | Overview of Dignity Care Intervention Ireland Project Role of Dignity Care Champion and DCI-IRELAND Education Co-facilitator |
| 145mins | The Concept of Dignity Current Role in providing palliative care Review of principles of communication in Palliative Care |
| | The Training Manual Patient Dignity Inventory (PDI) Dignity Care Intervention Framework |
| Session 2 | |
| Facilitator – Dr Michael Connolly, Head of Education AIHPC | |
| 3 hours | Informed Consent for research Using the Dignity Care Intervention Case Studies |

Appendix 7: Tool Analysis

| | Not a Problem | Slight problem | A problem | Major problem | Overwhelming problem | | |
|----|----------------------|-----------------------|------------------|----------------------|-----------------------------|------------|-------|
| | 1 | 2 | 3 | 4 | 5 | Blank no | total |
| | | | | | | | |
| | | | | | | | |
| 1 | 1 | 11 | 5 | 8 | | | 25 |
| 2 | 12 | 8 | 5 | | | | 25 |
| | | | | | | | |
| 3 | 8 | 13 | 4 | | | | 25 |
| | | | | | | | |
| 4 | 7 | 11 | 4 | 3 | | | 25 |
| 5 | 9 | 6 | 8 | 2 | | | 25 |
| 6 | 4 | 10 | 5 | 5 | 1 | | 25 |
| 7 | 13 | 5 | 5 | 2 | | | 25 |
| 8 | 15 | 4 | 4 | 1 | 1 | | 25 |
| | 69 | 68 | 40 | 21 | 2 | 199 | |
| | | 137 (68.84%) | 40 (20.10) | | 11.55 | 100% | |
| 9 | 11 | 8 | 4 | | | 2 | 25 |
| 10 | 10 | 7 | 8 | | | | 25 |
| 11 | 17 | 2 | 4 | 1 | | 1 | 25 |
| 12 | 4 | 11 | 8 | 1 | 1 | | 25 |
| 13 | 19 | 3 | 2 | | 1 | | 25 |
| 14 | 17 | 3 | 3 | 1 | 1 | | 25 |
| 15 | 13 | 4 | 4 | 2 | | 2 | 25 |
| 16 | 12 | 7 | 2 | 3 | | 1 | 25 |
| 17 | 12 | 8 | 4 | | | 1 | 25 |
| 18 | 12 | 9 | 1 | | 1 | 2 | 25 |
| 19 | 4 | 5 | 11 | 2 | 1 | 2 | 25 |
| 20 | 20 | | 4 | | | 1 | 25 |
| | | 75.69% | 19.02% | 5.20% | | | |
| | 151 (52.43) | 67 (23.26) | 55 (19.02) | 10 (3.47) | 5 (1.73) | 288 (100%) | |
| 21 | 12 | 7 | 5 | | | 1 | 25 |
| 22 | 19 | 2 | 2 | 1 | | 1 | 25 |
| 23 | 18 | 4 | 2 | | | 1 | 25 |
| 24 | 22 | | 2 | | | 1 | 25 |
| 25 | 11 | 8 | 4 | 1 | | 1 | 25 |
| 26 | 15 | 5 | 3 | | 1 | 1 | 25 |
| | | 85.41% | | 2.07% | | | |
| | 97 (67.36%) | 26 (18.05%) | 18 (12.50%) | 2 (1.38%) | 1 (0.69%) | 144 | |
| | 314 | 161 | 113 | 33 | 8 | | |
| | 49.92% | 25.60% | 17.97% | 5.25% | 1.27% | 0 | |



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