COMMUNITY NURSING
RESPONDING TO END OF LIFE CARE

DIGNITY CARE INTERVENTION IRELAND

Catriona Barry, Project Manager
Dignity Care Intervention (DCI) Ireland Pilot Project
AIM of Dignity Care Intervention Ireland Pilot Project

To Implement and Evaluate an Intervention that will be delivered by community nurses to help preserve the dignity of all individuals with palliative care needs living at home.
Palliative Care Clinical Programme for Ireland

‘To ensure that patients with life-limiting conditions and families can easily access a level of palliative care service that is appropriate to their needs regardless of care setting or diagnosis’

http://www.hse.ie/eng/about/Who/clinical/natclinprog/palliativecareprogr amme/
Dignity Care Intervention Project

**Phase 1**
Contextualising the DCI and Preparation for Implementation

**Phase 2**
Implementation of the DCI

**Phase 3**
Evaluation of the DCI
What does Dignity mean to you?
Why Dignity?

3 Focus Groups (n=3)
- Community Nurses Urban Setting
- Community Nurses Rural Setting
- Service User/Carer group
  (Voices4Care)
What did Community Nurses Say?

- ‘Dignity is listening to the patient and listening to the family’

- ‘Respecting the patient’

- ‘Everybody is an individual, you go to one house and one thing is very important and then you go to another house and that’s not relevant… so it’s really to leave your assumptions and preconceived ideas at the door and go in and listen and figure it out’

- ‘Supporting their choices, some people want to be at home and some people want to die at home and dignity is about supporting that choice as much as we can’

- ‘Allow the patient to be who they are’

- ‘Accepting people where they are at the moment’
What did Service Users/Carers say?

‘Dignity is Respect… Respect for the person who is no different just because they have a life limiting condition’

‘The Patient is still a person - You haven’t changed because you are now a patient’

‘Supporting normal activities… Maintaining as ‘Normal’ a life for the patient that can be achieved; given their problems… is the best that you can do’

‘Respect wishes of the person’

‘Confidentiality’

‘Preserving Autonomy’

‘Individual Care’

‘Privacy is part of Dignity…respecting patients privacy is very important’
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<th>Illness Related Concerns</th>
<th>Dignity Conserving Repertoire</th>
<th>Social Dignity Inventory</th>
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<td><strong>Level of Independence</strong></td>
<td><strong>Dignity Conserving Perspectives</strong></td>
<td><strong>Privacy Boundaries</strong></td>
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<td>Cognitive Acuity</td>
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<td>• generativity/legacy</td>
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<td>• death anxiety</td>
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<td></td>
<td>• living &quot;in the moment&quot;</td>
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<td>• maintaining normalcy</td>
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<td>• seeking spiritual comfort</td>
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Patient Dignity Inventory  Johnston et al 2011 Adapted with permission from Chochinov et al 2008

For each item, please indicate how much of a problem or concern these have been for you within the past few days

1 = NOT A PROBLEM     2 = A SLIGHT PROBLEM   3 = A PROBLEM
4 = A MAJOR PROBLEM   5 = AN OVERWHELMING PROBLEM

1. Experiencing physically distressing symptoms (such as pain, shortness of breath, nausea)
2. Feeling depressed
3. Feeling anxious
4. Feeling uncertain about my health
5. Worrying about my future
6. Not being able to carry out tasks associated with daily living (e.g. washing, getting dressed)
7. Not being able to attend to bodily functions independently (e.g. needing assistance with toilet related activities)
8. Not being able to think clearly
9. Feeling that how I look to others has changed significantly
10. Feeling like I am no longer who I was
11. Not feeling worthwhile or valued
12. Not being able to carry out important roles
13. Feeling that life no longer has meaning or purpose
14. Feeling that I have not made a meaningful and/or lasting contribution in my life
15. Feeling that I have unfinished business
16. Feeling that I don’t have control over my life
17. Not being able to accept the way things are
18. Feeling like I am no longer able to mentally cope with challenges to my health
19. Not being able to continue with my usual routines
20. Concern that my spiritual life is not meaningful
21. Feeling that care needs have reduced my privacy
22. Not feeling supported by my community of friends and family
23. Not feeling supported by my health care providers
24. Not being treated with respect or understanding by others
25. Feeling that I am a burden to others
26. Worries about how illness or death will affect my family or friends
### ILLNESS RELATED CONCERNS

<table>
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<th>Patient Dignity Inventory</th>
<th>Suggested Reflective Questions</th>
<th>Suggested Care Actions</th>
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</table>
| 1. Experiencing physically distressing symptoms | - What physical symptoms are causing you problems?  
- Tell me about the one that causes you most difficulty  
- What is the next one?  
- How have you/could you be helped to manage these symptoms? | - Make contact early to get to know the patient when well  
- Use communication skills of active listening and promote trust  
- Assess identified symptoms using evidence based assessment tools  
- Use local symptom guidelines (if available) re appropriate pharmacological intervention  
- Use local symptom guidelines (if available) re appropriate non-pharmacological intervention e.g. massage, touch, distraction etc.  
- Seek help/advice from relevant colleagues - GP, Specialist Palliative Care Nurse, Community Palliative Care Team, Physiotherapist, Occupational Therapist.  
- Teach the patient what is normal/abnormal for their condition  
- Support the patient/family members to contact appropriate services |

Johnston (2012) updated 2014. This has been produced for the purposes of the Dignity Care Intervention Pilot Project and cannot be reproduced without the authors permission.
The circle of care approach

Assess and Evaluate using Patient Dignity Inventory

Discuss identified sources of distress and how to address them Refl. Q and care actions

Use care actions agreed upon, seek help or refer if needed
Implications for Practice

- **Recognises** and **records** the Community Nursing contribution to end of life care
- Confirms the evidence base of nursing care activities **validating actions such as listening and providing comfort** to patients at the end of life
- Nurses are able to **identify dignity related concerns** from the patient’s viewpoint
- Nurses are able to **target** their care actions to meet the identified needs
DCI Ireland Project Team

**Principle Investigator**

**Dr. Sonja McIlfatrick (Co-PI)**
- Head of Research, All Ireland Institute of Hospice and Palliative Care/Reader in Nursing, University of Ulster

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**Prof. Bridget Johnston**

**Education Team**

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**Karen Charnley**
- AIIHPC Programme Manager, Education and Communications Hub
Dignity Care Intervention Ireland

4 Pilot Sites:
- Mid West
- Wicklow
- Dublin South Central
- Dublin South City
The Dignity Care Champion and DCI Education Co-Facilitator
Champions.

Communicate with colleagues on a regular basis in order to promote the health and well-being of individuals with palliative care needs by engaging in Dignity preserving practices.

Advocate on behalf of individuals with palliative care needs and their carers while maintaining a commitment to preserving the Dignity of Individuals by engaging in a person centred approach.

Information is shared with other project participants as well as organising and supporting colleagues in implementing the Dignity Care Intervention within clinical practice and participating in a network that shares local good practice with colleagues locally and nationally.
DCI Timeline (2013-2015)

Phase 1:
‘Contextualising’ the DCI & Preparation of the Education Package for DCI Training

- Project Manager Appointed
- 1st Project Team meeting (bi-monthly)
- 1st Steering Group meeting
- Field trip to Scotland
- Establish Expert Advisory Group
- IHF/ICS funding in place
- Seek Ethical Approval

Phase 2: Training & Implementation of the DCI within clinical practice

Aug 2013
- Project Manager Appointed
- 1st Project Team meeting (bi-monthly)
- 1st Steering Group meeting
- Field trip to Scotland
- Establish Expert Advisory Group
- IHF/ICS funding in place
- Seek Ethical Approval

Sept 2013
- IHF/ICS funding in place
- Seek Ethical Approval

Oct 2013 – Apr 2014
- IHF/ICS funding in place
- Seek Ethical Approval

May – Dec 2014
- IHF/ICS funding in place
- Seek Ethical Approval

January – Aug 2015
- IHF/ICS funding in place
- Seek Ethical Approval

Phase 3: Write up Project, Dissemination & Knowledge Transfer

On-going Evaluation

- IHF/ICS funding in place
- Seek Ethical Approval

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Project Outcomes of Dignity Care Intervention

• Improve **Partnership** across boundaries
• Develop the **role of the Public Health Nursing service** in the delivery of palliative care within primary care
• Contribute to the development and recognition of the importance of **palliative care within primary care settings**
• Improve **Quality** of care for palliative care patients and support informal caregivers
• Lead to wider expansion of ‘**Dignity Care’ practices/guidelines**
• Develop a culture of **shared learning**
References


THANK YOU

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