Patients’ and Families’ Perceptions of Palliative Care

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BACKGROUND AND MOTIVATION
Background
Preferences for palliative care

• Important to ensure resources are focused on services patients and their loved ones derive the greatest benefit from

• Different models + limited evidence
  - Delivery of palliative care services often influenced by national policy, funding arrangements and historical practices

• Evidence about preferences provides information about how services would best be delivered

• Caregivers may have different needs/preferences – important to balance these with patients’ preferences
Background
Perceptions of palliative care

- A negative perception of palliative care is a common barrier to the introduction of a palliative care approach or the introduction of specialist palliative care (SPC) services.
- Perceptions of palliative care have also been shown to influence patients’ preferences for place of care.
- There is little empirical evidence, however, on the perceptions and preferences of Irish patients and their loved ones.
- Similarly, there is little data on what may influence their preferences.
Motivation

- What works? For whom? What circumstances?
- Limited evidence about peoples’ preferences
  - What do they feel they need?
  - Similarities between patients and their family/friends
- Identifying the factors that may influence preferences for care
  - People may not understand the role of SPC services
  - Age, experience with SPC services, caregiver burden, etc.
Aim and Research Questions

**Aim:** To explore perceptions of palliative care among patients and family members accessing SPC services in Ireland and identify whether personal characteristics and geographical location are associated with expressed preferences for services.

**The key questions:**

1. Which characteristics of services and support are valued most by patients and their loved ones when living with a life-limiting illness?

2. How do perceptions and experiences of palliative care and hospice services, or other factors, influence these preferences?
METHODS
Methods
The International Access, Rights and Empowerment Plus (IARE+) Study

Study design

• Face-to-face survey
• Three regions across Ireland
• Preferences and perceptions of palliative care and hospice services
• Discrete choice experiment
Methods
Discrete Choice Experiments

• Participants make trade-offs between made-up scenarios
• Establish the importance of individual traits/characteristics of a service
  - What do they think the priorities are?
• Previously used in with people accessing palliative care
  - Day care, home care and over 65s
### Example of a DCE Choice Card

Which of these trips to the cinema would you prefer?

<table>
<thead>
<tr>
<th></th>
<th>Scenario A</th>
<th>Scenario B</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type of film</strong></td>
<td>A classic film</td>
<td>A new 3D release</td>
</tr>
<tr>
<td><strong>Price</strong></td>
<td>€5</td>
<td>€10</td>
</tr>
<tr>
<td><strong>Distance from home</strong></td>
<td>25 minutes</td>
<td>15 minutes</td>
</tr>
</tbody>
</table>

I would prefer: Scenario A [ ] Scenario B [ ]
# Example of DCE Choice Card

<table>
<thead>
<tr>
<th>Knowing whom to contact</th>
<th>Scenario A</th>
<th>Scenario B</th>
</tr>
</thead>
<tbody>
<tr>
<td>I do not know whom to contact when I have questions or need advice and I can’t find out</td>
<td></td>
<td>I know whom to contact when I have questions or need advice, but I often can’t get the answers I need</td>
</tr>
<tr>
<td>All services are free</td>
<td>€200 per month</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cost of care per month</th>
<th>Scenario A</th>
<th>Scenario B</th>
</tr>
</thead>
<tbody>
<tr>
<td>Automatically when something happens to me, like my quality of life gets worse</td>
<td></td>
<td>When I may have a short time left to live</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Access to palliative care services in community or hospital</th>
<th>Scenario A</th>
<th>Scenario B</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptoms significantly limit my ability to live the life I want</td>
<td></td>
<td>Symptoms somewhat limit my ability to live the life I want</td>
</tr>
<tr>
<td>Around 40 hours per week</td>
<td></td>
<td>Around 20 hours a week</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Impact of symptoms on my life</th>
<th>Scenario A</th>
<th>Scenario B</th>
</tr>
</thead>
<tbody>
<tr>
<td>The doctors provide advice and I make the decisions about my care</td>
<td></td>
<td>The doctors looking after me make the decisions about my care</td>
</tr>
<tr>
<td>I am cared for in the hospital as an inpatient</td>
<td></td>
<td>I am cared for in the hospice as an inpatient</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Amount of help at home I need from family and friends</th>
<th>Scenario A</th>
<th>Scenario B</th>
</tr>
</thead>
<tbody>
<tr>
<td>We have to find out about and arrange access to the services on our own</td>
<td></td>
<td>A healthcare professional provides information about services and helps us arrange access</td>
</tr>
<tr>
<td>Around 40 hours per week</td>
<td></td>
<td>Around 20 hours a week</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Arranging access to services</th>
<th>Scenario A</th>
<th>Scenario B</th>
</tr>
</thead>
<tbody>
<tr>
<td>The doctors provide advice and I make the decisions about my care</td>
<td></td>
<td>The doctors looking after me make the decisions about my care</td>
</tr>
<tr>
<td>I am cared for in the hospital as an inpatient</td>
<td></td>
<td>I am cared for in the hospice as an inpatient</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>How decisions are made</th>
<th>Scenario A</th>
<th>Scenario B</th>
</tr>
</thead>
<tbody>
<tr>
<td>I prefer:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Scenario A □**

**Scenario B □**
Palliative Care Questions
Likert scale questions

1. Strongly Agree
2. Agree
3. Neither Agree nor Disagree
4. Disagree
5. Strongly Disagree

_____ 1. Palliative care services are only available in the hospital or hospice.
_____ 2. Palliative care can only be offered by specialist teams.
_____ 3. Palliative care is as good as treatment from other hospital teams.
_____ 4. Palliative care is for people who are at the end of life.
_____ 5. Palliative care can provide support for family and friends.
_____ 6. Palliative care means giving up.
_____ 8. Palliative care focuses on improving a person’s quality of life.
_____ 9. Palliative care causes people to die before their time.
_____ 10. Palliative care is usually only offered to people who have been diagnosed with cancer.
### Hospice Services Questions

**Likert scale questions**

<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neither Agree nor Disagree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1. Hospices only provide inpatient care.
2. Hospices provide services at no cost.
3. The quality of treatment in the hospice is as good as in the hospital.
4. The hospice is for people who are at the end of life.
5. Being admitted to the hospice means you get no treatment.
6. The hospice can provide support for family and friends.
7. Services provided by the hospice focuses on improving quality of life.
8. Being admitted to the hospice causes people to die before their time.
9. Treatment as an inpatient in the hospice is usually only offered to people who have been diagnosed with cancer.
KEY FINDINGS
Patients’ Knowledge of Palliative Care
Regional differences

- Never heard of
- Heard a little
- Heard a lot
# Patients’ Experiences of Palliative Care

## Regional differences

<table>
<thead>
<tr>
<th></th>
<th>Region A (n=26)</th>
<th>Region B (n=25)</th>
<th>Region C (n=24)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>I know someone who used palliative care</td>
<td>4 16.7</td>
<td>10 41.7</td>
<td>8 33.3</td>
<td>36.0</td>
</tr>
<tr>
<td>I have used palliative care myself</td>
<td>19 79.2</td>
<td>19 79.2</td>
<td>24 100</td>
<td>44.0</td>
</tr>
<tr>
<td>From radio, television, newspaper or internet</td>
<td>0 -</td>
<td>0 -</td>
<td>1 4.2</td>
<td>2.7</td>
</tr>
<tr>
<td>From my family and friends</td>
<td>1 4.2</td>
<td>0 -</td>
<td>1 4.2</td>
<td>2.7</td>
</tr>
<tr>
<td>From others (specify)</td>
<td>2 8.3</td>
<td>0 -</td>
<td>1 4.2</td>
<td>1.3</td>
</tr>
</tbody>
</table>
Patients’ Perceptions of Palliative Care
All participants

- Palliative care services are only available in the hospital or hospice
- Palliative care can only be offered by specialist teams
- Palliative care is as good as treatment from other hospital teams
- Palliative care is for people near the end of life
- Palliative care can provide support for family and friends
- Palliative care means giving up
- Palliative care means you get no treatment
- Palliative care focuses on improving a person's quality of life
- Palliative care causes people to die before their time
- Palliative care is usually only offered to people with cancer

Legend:
- Strongly Agree or Agree
- Neither Agree or Disagree
- Strongly Disagree or Disagree
## Patients’ Experiences of Hospice
### Regional differences

<table>
<thead>
<tr>
<th></th>
<th>Region A (n=26)</th>
<th>Region B (n=25)</th>
<th>Region C (n=24)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>I know someone who used hospice services</td>
<td>8 (30.8)</td>
<td>8 (32.0)</td>
<td>11 (45.8)</td>
<td>36.0</td>
</tr>
<tr>
<td>I have used hospice services myself</td>
<td>25 (96.2)</td>
<td>3 (12.0)</td>
<td>5 (20.8)</td>
<td>44.0</td>
</tr>
<tr>
<td>From radio, television, newspaper or internet</td>
<td>0 (-)</td>
<td>0 (-)</td>
<td>2 (8.3)</td>
<td>2.7</td>
</tr>
<tr>
<td>From my family and friends</td>
<td>0 (-)</td>
<td>0 (-)</td>
<td>2 (8.3)</td>
<td>2.7</td>
</tr>
<tr>
<td>From others (specify)</td>
<td>0 (-)</td>
<td>1 (4.0)</td>
<td>0 (-)</td>
<td>1.3</td>
</tr>
<tr>
<td>I have not heard of hospice services</td>
<td>0 (-)</td>
<td>16 (64.0)</td>
<td>9 (37.5)</td>
<td>33.3</td>
</tr>
</tbody>
</table>
Patients’ Perceptions of Hospice
All participants

- Hospices only provide inpatient care
  - Strongly Agree or Agree: 60%
  - Neither Agree or Disagree: 20%
  - Strongly Disagree or Disagree: 20%

- Hospices provide services at no cost
  - Strongly Agree or Agree: 80%
  - Neither Agree or Disagree: 10%
  - Strongly Disagree or Disagree: 10%

- The quality of treatment in the hospice is as good as in the hospital
  - Strongly Agree or Agree: 70%
  - Neither Agree or Disagree: 20%
  - Strongly Disagree or Disagree: 10%

- The hospice is only for people near the end of life
  - Strongly Agree or Agree: 80%
  - Neither Agree or Disagree: 10%
  - Strongly Disagree or Disagree: 10%

- Being admitted to the hospice means you get no treatment
  - Strongly Agree or Agree: 0%
  - Neither Agree or Disagree: 100%

- The hospice can provide support for family and friends
  - Strongly Agree or Agree: 90%
  - Neither Agree or Disagree: 10%

- Services provided by the hospice focus on improving quality of life
  - Strongly Agree or Agree: 90%
  - Neither Agree or Disagree: 10%

- Being admitted to the hospice causes people to die before their time
  - Strongly Agree or Agree: 50%
  - Neither Agree or Disagree: 50%

- Treatment as an inpatient is usually only offered to people with cancer
  - Strongly Agree or Agree: 50%
  - Neither Agree or Disagree: 50%
Patients’ Perceptions of Hospice Services
Responses by Region

- Hospices only provide inpatient care
- Hospices provide services at no cost
- Quality of treatment in the hospice is as good as in the hospital

[Bar chart showing responses by region (A, B, C) for each statement, with colors indicating levels of agreement (Strongly agree or agree, Neither agree or disagree, Strongly disagree or disagree).]
Patients’ Perceptions of Hospice Services
Responses by Region

- Hospice is only for people who are near the end of life
- Hospice services focus on improving quality of life
- Being admitted to the hospice means you get no treatment

0%  20%  40%  60%  80%  100%

A       B       C
 A       B       C
 A       B       C

- Green: Strongly agree or agree
- Yellow: Neither agree or disagree
- Red: Strongly disagree or disagree
Group 1

- Limit Somewhat: 1.987
- Remain at home: 1.813
- Not Limited: 1.786
- Know, not always answers: 0.871
- Access to SPC any time: 0.09
- HCP helps arrange: 0.058
- Doctors make decisions: -0.110
- Know and always answers: -0.437
- Doctors make with patient: -0.746
- Hospice: -2.386

Group 2

- Know and always answers: 0.694
- Access to SPC any time: 0.503
- Limit Somewhat: 0.383
- Not Limited: 0.317
- HCP helps arrange: 0.248
- Hospice: 0.180
- Doctors make with patient: 0.159
- Remain at home: 0.125
- Know, not always answers: 0.121
- Doctors make decisions: -0.231
## Reported Experience with SPC Services

<table>
<thead>
<tr>
<th></th>
<th>Group 1</th>
<th></th>
<th>Group 2</th>
<th></th>
<th>(\chi^2) test</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
<td>P-value</td>
<td></td>
</tr>
<tr>
<td>I know someone who used hospice services</td>
<td>7</td>
<td>33.3</td>
<td>17</td>
<td>37.8</td>
<td>0.727</td>
</tr>
<tr>
<td>I have used hospice services myself</td>
<td>5</td>
<td>23.8</td>
<td>22</td>
<td>48.9</td>
<td>0.054</td>
</tr>
<tr>
<td>From radio, television, newspaper or internet</td>
<td>1</td>
<td>4.8</td>
<td>1</td>
<td>2.2</td>
<td>0.575</td>
</tr>
<tr>
<td>From my family and friends</td>
<td>1</td>
<td>4.8</td>
<td>0</td>
<td>-</td>
<td>0.140</td>
</tr>
<tr>
<td>From others (specify)</td>
<td>0</td>
<td>-</td>
<td>1</td>
<td>2.2</td>
<td>0.491</td>
</tr>
<tr>
<td>I have not heard of hospice services</td>
<td>11</td>
<td>52.4</td>
<td>13</td>
<td>28.9</td>
<td>0.065</td>
</tr>
</tbody>
</table>
Loved Ones’ Knowledge of Palliative Care

Regional differences

A

B

C

Never heard of  Heard a little  Heard a lot

Trinity College Dublin, The University of Dublin
Loved Ones’ Perceptions of Palliative Care
All participants

- Palliative care services are only available in the hospital or hospice
- Palliative care can only be offered by specialist teams
- Palliative care is as good as treatment from other hospital teams
- Palliative care is for people near the end of life
- Palliative care can provide support for family and friends
- Palliative care means giving up
- Palliative care means you get no treatment
- Palliative care focuses on improving a person's quality of life
- Palliative care causes people to die before their time
- Palliative care is usually only offered to people with cancer

0%  20%  40%  60%  80%  100%

- Strongly agree/agree
- Neither agree or disagree
- Strongly disagree/disagree
## Loved Ones’ Experiences of Hospice

### Regional differences

<table>
<thead>
<tr>
<th>Experience</th>
<th>Region A (n=22)</th>
<th>Region B (n=25)</th>
<th>Region C (n=20)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N%</td>
<td>N%</td>
<td>N%</td>
<td></td>
</tr>
<tr>
<td>I know someone who used hospice services</td>
<td>22 (100)</td>
<td>11 (44.0)</td>
<td>8 (40.0)</td>
<td>61.2</td>
</tr>
<tr>
<td>I have used hospice services myself</td>
<td>4 (18.2)</td>
<td>0 (-)</td>
<td>0 (-)</td>
<td>6.0</td>
</tr>
<tr>
<td>From radio, television, newspaper or internet</td>
<td>0 (-)</td>
<td>0 (-)</td>
<td>6 (30.0)</td>
<td>10.5</td>
</tr>
<tr>
<td>From my family and friends</td>
<td>0 (-)</td>
<td>2 (8.0)</td>
<td>6 (30.0)</td>
<td>11.9</td>
</tr>
<tr>
<td>From others (specify)</td>
<td>3 (13.6)</td>
<td>4 (16.0)</td>
<td>5 (26.3)</td>
<td>17.9</td>
</tr>
<tr>
<td>I have not heard of hospice services</td>
<td>0 (-)</td>
<td>13 (52.0)</td>
<td>2 (10.0)</td>
<td>24.6</td>
</tr>
</tbody>
</table>
Loved Ones’ Perceptions of Hospice
All participants

- Hospices only provide inpatient care
- Hospices provide services at no cost
- The quality of treatment in the hospice is as good as in the hospital
- The hospice is only for people near the end of life
- Being admitted to the hospice means you get no treatment
- The hospice can provide support for family and friends
- Services provided by the hospice focus on improving quality of life
- Being admitted to the hospice causes people to die before their time
- Treatment as an inpatient is usually only offered to people with cancer

- [Green] Strongly Agree or Agree
- [Yellow] Neither Agree or Disagree
- [Red] Strongly Disagree or Disagree
Loved Ones’ Perceptions of Hospice
Regional differences

Hospices only provide inpatient care
- Strongly agree or agree: A, B, C
- Neither agree or disagree: A
- Strongly disagree or disagree: A

Hospices provide services at no cost
- Strongly agree or agree: A, B, C
- Neither agree or disagree: A
- Strongly disagree or disagree: A

Treatment as an inpatient is usually only for those with cancer
- Strongly agree or agree: A, B, C
- Neither agree or disagree: A
- Strongly disagree or disagree: A
Doctors make decisions

Group 1

Hospice: 0.541
HCP helps arrange: 0.497
Know and always answers: 0.399
Know, not always answers: 0.378
Access to SPC any time: 0.369
Limit Somewhat: 0.143
Not Limited: -0.115
-0.362
-0.465
-0.713

Group 2

Remain at home: 2.027
Access to SPC any time: 0.029
Know and always answers: 2.387
Know, not always answers: 0.842
HCP helps arrange: 0.605
Limit Somewhat: 1.049
Not Limited: 1.162
-1.308
-0.243
-1.304

Group 3

Know and always answers: 3.466
HCP helps arrange: 2.706
Access to SPC any time: 1.995
Remain at home: 1.783
Doctors make with patient: 1.360
Limit Somewhat: 1.089
Know, not always answers: 0.374
-0.224
-2.615
-3.952

Doctors make decisions
Remain at home
Hospice
# Reported Experience with SPC Services

<table>
<thead>
<tr>
<th></th>
<th>Group 1</th>
<th></th>
<th>Group 2</th>
<th></th>
<th>Group 3</th>
<th></th>
<th>( \chi^2 ) test</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>I know someone who used hospice services</td>
<td>19</td>
<td>61.3</td>
<td>13</td>
<td>65.0</td>
<td>9</td>
<td>56.3</td>
<td></td>
<td>0.866</td>
</tr>
<tr>
<td>I have used hospice services myself</td>
<td>2</td>
<td>6.5</td>
<td>1</td>
<td>5.0</td>
<td>1</td>
<td>6.3</td>
<td></td>
<td>0.976</td>
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<tr>
<td>From radio, television, newspaper or internet</td>
<td>5</td>
<td>16.1</td>
<td>2</td>
<td>10.0</td>
<td>0</td>
<td>-</td>
<td></td>
<td>0.230</td>
</tr>
<tr>
<td>From my family and friends</td>
<td>5</td>
<td>16.1</td>
<td>3</td>
<td>15.0</td>
<td>0</td>
<td>-</td>
<td></td>
<td>0.239</td>
</tr>
<tr>
<td>From others (specify)</td>
<td>5</td>
<td>16.1</td>
<td>6</td>
<td>30.0</td>
<td>1</td>
<td>6.3</td>
<td></td>
<td>0.171</td>
</tr>
<tr>
<td>I have not heard of hospice services</td>
<td>6</td>
<td>19.4</td>
<td>2</td>
<td>10.0</td>
<td>7</td>
<td>43.8</td>
<td></td>
<td>0.047</td>
</tr>
</tbody>
</table>
SUMMARY AND CONCLUSION
Summary

Perceptions of palliative care and hospice services

• Participants broadly understood the principles of palliative care, with 80% agreeing that palliative care was about quality of life and offering support to family and friends.

• However, many participants held incorrect assumptions about important aspects of service delivery.
  - Nearly 80% thought palliative care could only be provided by SPC teams, while 30% thought palliative care is only available in a hospice or hospital.
  - More than half thought SPC services are primarily for people who are near the end of life.

• Perceptions varied across the study regions and influenced expressed preferences.
Summary
Perceptions of palliative care and hospice services

• Surprising that a minority of patients (14%) did not realise they were using palliative care services.
  - Variation in reported usage across the study regions was statistically significant, with 80% of participants in Regions A and B stating they had used palliative care compared to 100% in Region C. These results likely reflect differences in terminology used across the settings.

• The findings show the challenges in asking about preferences for services which aren’t defined in a consistent manner.
  - The need for a common language and definition of palliative care to improve knowledge among the public and health care professionals has been highlighted in previous research.
Concluding Thoughts
Perceptions of palliative care and hospice services

• Despite a long history of palliative care provision in Ireland, significant misperceptions exist, even among people accessing services.

• These data demonstrate there is an ongoing need to improve public awareness and understanding of palliative care and highlights the areas that should be prioritised.

• Appropriate knowledge about services is critical to helping people make informed choices about their care.
Thank You