Relational Elements of End of Life Anticipatory Care Planning Implementation

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Background
- Strategic Framework for Action 2021: “People... have timely and focused conversations... to plan their care and support towards the end of life”.
- Dumfries and Galloway (DG) has higher deaths than the UK average at home, in the community setting, as well as in the in-hospital hospice.
- Measuring the success of anticipatory care planning (ACP) solely with task oriented elements such as documentation or place of death may not reflect the philosophy-based person-centred process that is important to patients, which may also be diluted by individual, relational, and organisational constraints.1,2
- The 'complex' relational elements of ACP are rarely measured compared to instrumental/clinical task oriented elements.3

Aims
To explore to what extent and in which contexts end of life ACP discussions and documentation is being operationalised in DG.
To identify individual, relational, and structural challenges to implementation.
To determine the effect different elements of ACP have and why.

- Data collection and analysis are still ongoing -

Results
ACP aim: Professionals provide ACP opportunity for expected death
73% of cases GPs initiated ACP.
For 41% of patients their understanding of prognosis was discussed and they were fully aware.

Were the patient’s goals and preferences in case he/she couldn’t make their own decisions discussed? (n=69)
- Yes: 23%; No:42%
- Not relevant/unknown: 35%

ACP aim: Timely, helpful, and dynamic ACP record is created and shared

<table>
<thead>
<tr>
<th>Cause of death (82.3% had comorbidity)</th>
<th>% KIS before death</th>
<th>Time before death (wks)</th>
<th>IQR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer (n=38)</td>
<td>87%</td>
<td>28</td>
<td>(2-23)</td>
</tr>
<tr>
<td>Organ failure (n=56)</td>
<td>58%</td>
<td>76</td>
<td>(14-138)</td>
</tr>
<tr>
<td>Dementia/frailty (n=33)</td>
<td>79%</td>
<td>109</td>
<td>(51-162)</td>
</tr>
<tr>
<td>Total (N=127)</td>
<td>72%</td>
<td>77</td>
<td>(13-137)</td>
</tr>
</tbody>
</table>

22% of individuals had their preferred place of final care/death recorded.
ACP processes were considered sufficient or very sufficient by GPs in 66% of expected deaths.

How dynamic was the process?

Acclimatisation Index (n=67)
- Not at all important: 15%
- Not very important: 42%
- Somewhat important: 11%
- Important: 2%
- Very important: 20%

Time spent in a hospital
- Home: 35/21; Residential home: 11/11; Hospital 3/2; Community hospital: 4/3

Place of death (survey): preferred / actual
- Home: 35/21; Residential home: 11/11; Hospitlal 3/2; Community hospital: 4/3

How often did you discuss ACP with the patient for family? (n=67)
- Never: 8%
- Once: 16%
- Twice: 21%
- 3 times or more: 19%
- Unknown/Not relevant: 12%

Barriers
When you have ACP discussions with patients/families, how comfortable does it feel?
- Very uncomfortable: 10%
- Completely uncomfortable: 1%
- Not uncomfortable: 22%
- Not very important: 21%
- Somewhat important: 6%
- Important: 5%
- Very important: 1%

Methods
A survey based on Normalisation Process Theory (NPT) to explore views on implementation was adapted.4 NPT explains the process of implementing complex interventions in terms of the coherence, cognitive participation, collective action, and reflexive monitoring of professionals.5

A retrospective decedent patient specific survey was designed to explore the journey and the ACP that was done, building on general beliefs and the audit data extracted from medical records.

Data Collection (ongoing)
1. 18 GPs from practices representative of the various levels of urban/rural classification in DG were recruited
2. Data from general NPT survey, completed by GPs and specialist palliative care (n=37)
3. Timely, to allow for recall, retrospective decedent patient specific survey with open questions (n=67) completed by GPs and audit data extracted from medical records (n=127)

Data Analysis (ongoing)
Triangulating descriptive statistics and qualitative question responses

Elements that were part of ACP discussions with patient (n=66)

Ask me about more relevant and preliminary discussion points

References: