What outcome domains are considered core to assessing the impact of adult specialist palliative care services in Wales? A rapid review.

20/12/21

Context

Assessment of palliative care delivery is essential for managing service performance and providing improvement in care (Donabedian, 2005). However, such assessments have tended to focus on capturing process related outcomes (service volume, response times etc.) to demonstrate service activity, rather than consistently measuring impact of services on patient and family.

There has been increasing emphasis on, and international consensus on the need for, outcomes which focus more specifically on impact, in particular on domains such as quality, effectiveness and efficiency of palliative care rather than just service activity (Davis et al., 2013, Clark et al., 2016).

Recently, there have been several initiatives to standardise approaches to this type of outcome assessment and to encourage regional approaches which will meet local needs but also allow benchmarking at national and international levels.

In Wales, the End-of-Life Board (EoLB) has prioritised the need to establish a standardised approach to the collection of this type of data set, by establishing a consensus on the domains of importance and to identify whether an existing approach such as the Outcome Assessment and Complexity Collaborative (OACC) (Witt et al., 2014) or Palliative Care Outcomes Collaboration (PCOC) (Eager et al., 2010), may meet ‘needs’ in Wales or whether the specific health and social care economy unique to Wales mandates for additional or different domains of care to be addressed. This project is a multi-stage study, with this first stage rapid review identifying from the published literature those outcomes for adult palliative care services that are considered most important to capture in order to assess service quality.

Key Findings

In total, database and supplementary searches generated 635 citations. After removing duplicates and irrelevant records 254 records were screened for eligibility. Figure 1 represents the flow of information through the different phases of the review.

Inclusion: Adult palliative care services; OECD countries; guidelines on domains of relevance to assessment of SPC care delivery and/or tolls and systems being implemented to capture that data.

Exclusion: Studies set in non-Organization for Economic Cooperation and Development (OECD) countries; Case series studies consisting of less than 25 patients; and non-English language studies.

Study selection/Quality Assessment/Data Extraction

Study selection and data extraction was carried out by two independent reviewers. The full text was assessed independently using a pre-designed eligibility form according to inclusion criteria. Data extraction form was piloted to ensure ease and accuracy of data. Quality assessment was not undertaken due to the type of the topic and research question.

Using a deductive process, individual outcomes were identified from each of the nine studies and mapped across into a classification framework to help conceptualise and compare constructs. Table 2 consists of the outcomes mapped to outcome domains.

Any discrepancies between the two reviewers were resolved by consensus or by recourse to a third reviewer.

Review Methods

Search Strategy: A systematic search was conducted across a wide-ranging set of databases: Ovid Medline, including In-Process & Other Non-Indexed Citations, Ovid PsychINFO, Ovid HMIC, Ebsco CINAHL & Scopus via Elsevier.

The preliminary search strategy was developed on Ovid Medline using both text words and Medical subject headings from January 2011 to February 2021 restricted to English language articles/resources and research with human participants. The search strategy was modified to capture indexing systems of the other databases. (Search strategies available upon request).

To identify additional papers, electronic tables of content for the last two years were scanned for:

- BMJ Supportive & Palliative Care
- Palliative Medicine

Furthermore a search was carried out in Google Scholar and reference lists of systematic reviews were checked for any relevant studies. The search generated 635 citations after removing duplicates and irrelevant records. Figure 1 represents the flow of information through the different phases of the review.

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Evidence Implications:

Clinical & Policy

The long list of domains and outcomes generated from the table, will be taken forward to a palliative care expert group, where a consensus process will take place and a final outcome set for measuring the quality of palliative care across Wales will be generated.

Strengths & Limitations

A strength of this review is that a deductive, consensus approach was taken when mapping outcomes into domains. This allowed for flexibility and movement of outcomes between domains in order to reach a finalized agreed longlist to take forward to an expert workshop group.

Limitations of this review include an absence of quality appraisal of included studies. However, for the purpose of this study, outcome data was not synthesized as such and therefore quality appraisal of included studies was not deemed necessary. Most studies included were from the United States, where the health care system differs to that in the UK. This may have effects on the generalisability of the reported outcomes and subdomains.

Glossary:

National Consensus Project (NCP)
Outcome Assessment and Complexity Collaborative (OACC)
Organisation for Economic Co-operation and Development (OECD)
Palliative Care Outcomes Collaboration (PCOC)
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Figure 2—Consensus Mapping Process

Table 1—Outcome Domains

<table>
<thead>
<tr>
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<tbody>
<tr>
<td>1. Structure and process of care</td>
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<tr>
<td>2. Physical Aspects of care</td>
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<tr>
<td>3. Psychological/Psychiatric aspects of care</td>
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<tr>
<td>4. Social aspects of care</td>
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<tr>
<td>5. Spiritual/religious/existential aspects of care</td>
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<tr>
<td>6. Cultural Aspects of care</td>
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<tr>
<td>7. Care nearing end of life</td>
</tr>
<tr>
<td>8. Ethical and legal aspects of care</td>
</tr>
<tr>
<td>9. Overall wellbeing</td>
</tr>
<tr>
<td>10. Information and preferences</td>
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Table 2— Outcomes mapped to outcome domains

<table>
<thead>
<tr>
<th>Domain</th>
<th>Outcomes (From extracted studies)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Structure and process of care</strong></td>
<td>Comprehensive assessment&lt;br&gt;Adverse events and staff distress&lt;br&gt;Medication adherence in institutional setting&lt;br&gt;Length of unstable phase&lt;br&gt;Timing and duration of distress&lt;br&gt;Screening for symptoms&lt;br&gt;Nature of care delivery, accessible, timely and knowledgeable.&lt;br&gt;Continuity of care&lt;br&gt;Culture of supporting palliative care&lt;br&gt;Accessibility to service&lt;br&gt;Timing of assessment&lt;br&gt;Skill mix of multi-disciplinary team&lt;br&gt;Proportion of service users assessed (per time period)&lt;br&gt;Breathlessness management&lt;br&gt;Pain treatment&lt;br&gt;Treatments of psychological symptoms</td>
</tr>
<tr>
<td><strong>Physical Aspects of care</strong></td>
<td>Screening for physical symptoms&lt;br&gt;Pain assessment&lt;br&gt;Fatigue&lt;br&gt;Nausea &amp; Vomiting&lt;br&gt;General physical symptoms&lt;br&gt;Comfort&lt;br&gt;Physical symptom improvement&lt;br&gt;Breathlessness assessment</td>
</tr>
<tr>
<td><strong>Psychological/Psychiatric aspects of care</strong></td>
<td>Discussion of emotional needs&lt;br&gt;Feeling safe in institution&lt;br&gt;Depression/psychological care&lt;br&gt;Overall emotions including loneliness&lt;br&gt;Psychological needs addressed&lt;br&gt;Cognitive dysfunction</td>
</tr>
<tr>
<td><strong>Social aspects of care</strong></td>
<td>Family anxiety&lt;br&gt;Family wellbeing&lt;br&gt;Family carer burden&lt;br&gt;Social Care&lt;br&gt;Family Relationships&lt;br&gt;Relationship with carer&lt;br&gt;Family Support&lt;br&gt;Family involvement&lt;br&gt;Family experience&lt;br&gt;Accessibility to family</td>
</tr>
</tbody>
</table>
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### Table 2 Continued — Outcomes mapped to outcome domains

<table>
<thead>
<tr>
<th>Domain</th>
<th>Outcomes (From extracted studies)</th>
</tr>
</thead>
</table>
| Spiritual/religious/existential aspects of care | Discussion of religious/spiritual/existential concerns  
Feeling at peace  
Religious beliefs  
Beliefs and values                                      |
| Cultural Aspects of care                   | Cultural Beliefs                                                                                  |
| Care nearing end of life                   | Last week of life care  
Palliative care options  
End-of-life care decisions  
Place of death  
End of life preferences                           |
| Ethical and legal aspects of care          | Documentation of surrogate  
Treatment preferences  
Care consistency  
Documented care preferences/documentation  
Advanced directive documentation                  |
| Overall wellbeing                          | Quality of life                                                                                   |
| Information and Preferences                | Communication of clear information  
Discussion of preferences of Place of care  
Information needs of family and patient  
Patient treatment preferences  
Involvement in decision making  
Exchange of clinical information across caregivers, disciplines, and settings. |
What outcome domains are considered core to assessing the impact of adult specialist palliative care services in Wales? A rapid review.

Included Studies:


Additional references:

- Donabedian A. Evaluating the Quality of Medical Care, The Milbank Quarterly 2005; 83(4):691-729.

Additional materials available upon request:

- Data extraction forms
- Search strategies
- List of excluded studies

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PaCERSWCRC@cardiff.ac.uk

Disclaimer: Palliative Care Evidence Review Service (PaCERS) is an information service for those involved in planning and providing palliative care in Wales. Rapid reviews are based on a limited literature search and are not comprehensive, systematic reviews. This review is current as of the date of the literature search specified in the Review Methods section. PaCERS makes no representation that the literature search captured every publication that was or could be applicable to the subject matter of the report. The aim is to provide an overview of the best available evidence on a specified topic using our documented methodological framework within the agreed timeframe.