How is quality of life defined by palliative care patients?

A systematic review & synthesis of qualitative research

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Overview

• Economic evaluation in palliative care
• Systematic review
• Framework synthesis
• Key themes
• Implications for measuring benefits in palliative care economic evaluations
Economic evaluation

McCaffrey, N & Currow, D
BMJ Supportive & Palliative Care 2015
Measuring benefits

- Quantity **AND** quality

- **Health-related** quality of life
  
  - **EQ-5D**: Anxiety; pain; mobility; self-care; usual activities
  
  - **SF-6D**: Mental health; pain; physical function; role limitation; social function; vitality


Aims

- To determine the QOL domains important to adults receiving palliation from their own perspective for validating preference-based instruments used in economic evaluations.

- To compare and contrast important aspects of QOL according to country of origin, primary diagnosis, living arrangements and proximity to death.
<table>
<thead>
<tr>
<th>Methods</th>
<th>Databases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Search terms</td>
<td>Databases</td>
</tr>
<tr>
<td>Palliative</td>
<td>1. ASSIA</td>
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<tr>
<td>Terminally ill</td>
<td>2. CINAHL</td>
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<tr>
<td>Qualitative</td>
<td>3. Cochrane Library</td>
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<tr>
<td>Quality of life</td>
<td>4. Embase</td>
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<tr>
<td>Quality of dying</td>
<td>5. Medline</td>
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<td></td>
<td>6. Psychinfo</td>
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<td>7. Pubmed</td>
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</table>
# Inclusion criteria

<table>
<thead>
<tr>
<th>Study Design</th>
<th>Study Population</th>
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<tbody>
<tr>
<td>Qualitative methodologies</td>
<td>People ≥18 years of age</td>
</tr>
<tr>
<td>Report original data</td>
<td>Life-limiting illness</td>
</tr>
<tr>
<td>Analysis with quotations</td>
<td>Receiving palliation</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Study Aim</th>
<th>Study Publication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of life is the focus</td>
<td>English language</td>
</tr>
<tr>
<td>No pre-conceived list</td>
<td>Peer-reviewed journal</td>
</tr>
</tbody>
</table>
Study selection

• **Titles and abstracts**
  - Reviewed in full by the primary author & a research assistant
  - A second reviewer independently screened 10%

• **Full text reports**
  - Retrieved for all citations appearing to meet the inclusion criteria or where there was uncertainty
  - Reviewed by the primary author
  - Pearling
Data analysis

THEMES

Mapping & interpretation

Charting

Indexing

Familiarisation

Initial framework
Records identified through database searching (n = 4,928)

Additional records identified through pearling (n = 5)

Records after duplicates removed (n = 2,849)

Records screened (n = 2,849)

Records excluded (n = 2,663)

Full-text articles assessed for eligibility (n = 186)

Full-text articles excluded (n=167)
   - Incorrect study aim (n=77)
   - Incorrect population (n=36)
   - Raw data not reported (n=21)
   - Incorrect data collection method (n=16)
   - Pre-determined domains or questionnaire administered before interview (n=11)
   - Not peer-reviewed (n=6)

Studies included in qualitative synthesis (n = 19)
# Included studies

<table>
<thead>
<tr>
<th>Country</th>
<th>Setting</th>
<th>Setting Count</th>
<th>Diagnoses</th>
<th>Diagnoses Count</th>
<th>Focus</th>
<th>Focus Count</th>
<th>Type of analysis</th>
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<tbody>
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<td>Community</td>
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<td>Cancer</td>
<td>12</td>
<td>QOL</td>
<td>12</td>
<td>Thematic</td>
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<td></td>
<td>Hospital</td>
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<td>HF</td>
<td>2</td>
<td>GD</td>
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<td>USA</td>
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<td>AIDS</td>
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<td>S Africa</td>
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</tbody>
</table>

GD = good death; HF = heart failure; NZ = New Zealand; NS = not stated; QOL = quality of life
"To be able to go out, to enjoy the trees and the air and the flowers and the colours, and to hear the birds singing, that's QOL."
(Cohen, 2002)
Personal Autonomy

"My responsibilities toward my life, my body, my decisions - I'm in control of that... I am the one that will say what I want... He has given me a tool that will give me QOL till the end, and I think this is a great gift that I have received."

(Sherman, 2001)

"I guard my independence. I want to do what I can for myself. I am no different from other people who are in life-threatening situations."

(Gourdji, 2009)
We have spoken about so many things... we have our own home, have a very large garden and are both avid gardeners; now she [wife] has to do it all by herself. And it may sound a bit strange but we have had time to discuss how to do the chores...It is maybe a bit weird to say, to organize these materialistic things now, but you worry about it. I don’t think I’m the only one who wants to leave everything behind as good as possible.”

(Goldsteen, 2006)
“I’ve no fear of dying. I used to have. I used to think, how will they know if I’m dead, you know, all sorts used to go through my mind, but not now. I think I’ve eternal life so I’ve that to look forward to, so that’s all right as well. No, I’ve no fear of dying.”

(Gott, 2008)

“My life has a great deal of meaning. I know that I have served my fellow man, and that’s one of the keys to having a happy life.”

(Greisinger, 1997)
Thematic patterns?

• Individual studies (N=19)
  - All reported emotional and spiritual aspects
  - Most reported physical (n=18), social (n=18) and individual aspects (n=14) and aspects of personal autonomy (n=14)

• Study characteristics
  - Only American (n=5) & Canadian studies (n=3) included cognitive aspects
  - Only Canadian & New Zealand studies, and those including participants with cancer mentioned the environment
  - Preparatory aspects mentioned in studies conducted in all settings, except hospice only
<table>
<thead>
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<th>Questionnaire</th>
<th>Domains/ dimensions</th>
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<tr>
<td>HUI3</td>
<td>Ambulation; cognition; dexterity; emotion; hearing; pain; speech; vision</td>
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<tr>
<td>AQoL</td>
<td>Coping; independent living; life satisfaction; mental health; pain; relationship; self worth; senses</td>
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Conclusion

Popular, preference-based instruments such as the EQ-5D and SF-6D are inappropriate as stand alone measures of benefit in palliative care economic evaluations.
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THANKS
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References

25. Carroll C, Booth A. Quality assessment of qualitative evidence for systematic review and synthesis: Is it meaningful, and if so, how should it be performed? Research Synthesis Methods 2014:n/a-n/a.
References


Dr Nikki McCaffrey Aug 2015
Quality

Carroll et al reporting quality criteria

1. The question & study design
   Choice of design given & explained

2. The section of participants
   Explicitly described, eg purposive

3. Methods of data collection
   Details provided, eg topic guide for interview

4. Methods of analysis
   Details given, eg transcription & form of analysis