Quality of Life at the End of Life:
Evaluating the Clinical Utility of the QUAL-EC in Patients with Advanced Cancer

13th Australian Palliative Care Conference 2015
Melbourne, Australia
October 1st – 4th

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Advanced cancer patients have high levels of unmet needs

- Research shows in palliative care populations distress associated with physical symptoms, perceived loss of control & existential concerns

- Improving QOL is a fundamental goal of care for advanced cancer patients

- QOL examines a patient’s own subjective well-being, feelings and concerns

- NO universally accepted definition but agree QOL is:
  
  Subjective / Multidimensional / Dynamic (changing)

- 4 broad domains: physical, psychological, social, spiritual

- Monitoring QOL recommended to identify: distress, symptom burden, functional/psycho-social needs
Widely used cancer QoL tools are:

- lengthy, demanding on very ill
- focus on identifying negatives in patient clinical and physical status re: tx and future tx
- miss important psycho-social issues of importance

EORTC-QLQ-C30 (30 items)  FACT-G/FACIT-PAL (46 items)

- Shortened versions still compromise social/emotional & focus on symptoms and negative concerns
- Short/efficient, reliable instruments that address positive and negative elements, psycho-social issues are needed
- **Focuses** on domains known to be important at EOL
Quality of Life at the End of Life (QUAL-E/QUAL-EC)

- Identified the QUAL-E (25 items; 21 items, 2011 version reduced to 17)
  - Inductively developed in the US with two focus group studies of patients, families and clinicians and a national survey in early 2000s
  - QUAL-E Domains: (4 domain scores/no total score)
    - Symptom impact;
    - Relationship with healthcare provider;
    - Preparation for end of life (concerns about loved ones);
    - Life completion

- Original psychometric testing established robustness
- Structural validity, internal consistency, test-retest reliability, sensitivity to change, and construct validity
Tested **QUAL-E** (21 items) in palliative **inpatients** (n=52) for suitability in two hospitals (86% pts cancer; 44% men; mean age: 67)

- Although developed as a **self-administered**, 83% requested **interview** (n=43)

**Despite difficulty with some questions, patients**

- Able to **appropriately** answer the instrument items,
- Found the content of the questions **suitable**,
- Appreciated contributing to research to help others, and
- Found the opportunity to **reflect** upon their individual experience and give voice to their thoughts and feelings **meaningful**

**Acceptability and face validity** in Australian palliative inpatients

**Interview format and/or potential items prompted patients to express unmet needs and opportunities to provide psychosocial support**

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Follow Up Study

- Evaluate whether **QUAL-E domain scores indicate clinically relevant problems** and psychological “distress”

- Psychological distress is associated with poorer patient outcomes, including lower QOL.

- In palliative care populations, distress linked to:
  - *Physical symptoms*, in particular pain,
  - Perceived *loss of control*,
  - *Existential concerns* such as relationship worries, feelings of hopelessness, fear of burdening loved ones, and
  - *Difficulties* with preparation for end-of-life

- **Hypothesis:**
  
  **Exploring patients’ responses to the QUAL-E domains in-depth offers scope to identify the patient experience domains driving distress that may provide opportunities for intervention.**
To evaluate the utility and feasibility of the QUAL-EC as a potential aid to the clinical care of patients with advanced cancer.

The specific objectives were to:

- Explore associations between QUAL-EC domain scores and a self-rated measure of distress (Distress Thermometer).
- Explore responses to the QUAL-EC when administered only as an interview.
- Assess participants’ responses to using the QUAL-EC during episodes of inpatient or outpatient care.
**Methods**

*Design:* cross-sectional, mixed methods design  

*Setting:* 610-bed Australian tertiary hospital providing comprehensive cancer care  

*Participants:* \((N=50)\) Convenience sample of  
- hospitalised patients receiving palliative care services \((n=25)\) and  
- ambulatory patients attending either of designated out-patient clinics: medical oncology and palliative care \((n=25)\)

*Clinical staff identified patients who met the following inclusion criteria:*  
- diagnosed with advanced cancer with a prognosis of one year or less;  
- aged 18 years or older;  
- able to speak and read English;  
- cognitively intact;  
- physically and emotionally able to participate; and  
- able to provide written informed consent.
**Measures**

**QUAL-EC**
- Initially a 25-item instrument covering 4 domains and global QOL.
- In 2011, a **reduced 17-item instrument**, the QUAL-E-Cancer (QUAL-EC) validated with 464 Canadian patients with advanced cancer (2)

**Distress Thermometer (DT)**
- A **brief self-report tool** measuring patients’ psychological distress over the previous seven days.
- The DT is a visual analogue scale ranging from zero (no distress) to 10 (extreme distress)
- >4 detects psychological distress and a score of >7 indicates need for referral

**Feasibility:** 5 study-specific closed-answer questions

Data collection:

- Participants provided demographic information and then completed the DT as a self-report.
- QUAL-EC then administered as a structured interview, digitally recorded.
- Lastly, participants completed the brief feasibility survey.

Data analysis:

- **Descriptive statistics** for patient characteristics/feasibility survey responses.
- **Summary statistics** (means and SD) were obtained for the DT scores/QUAL-EC domains.
- **Frequency tables** for dichotomous variables contained in the DT problem list.
- **Relationships** between patients’ QUAL-E domain scores and DT scores were investigated using **correlation and regression analyses**.
- Digital recordings of interviews were transcribed verbatim and subjected to **thematic analysis** to provide context to patients’ responses.
- **Interview transcripts** were reviewed using a matrix to tabulate QUAL-EC questions that a) presented difficulties for patients (and the nature of those difficulties); b) generated substantive comments; or c) were completed as self-report.
<table>
<thead>
<tr>
<th>N=50</th>
<th>Demographics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>60 years</td>
</tr>
<tr>
<td>Mean</td>
<td>Range</td>
</tr>
<tr>
<td><strong>Gender %</strong></td>
<td>66 % Male</td>
</tr>
<tr>
<td><strong>Diagnosis %</strong></td>
<td>26% Mesothelioma</td>
</tr>
<tr>
<td><strong>Time since diagnosis</strong></td>
<td>0-3 months (n=15)</td>
</tr>
</tbody>
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The only significant demographic variation between participant groups was that outpatients were significantly more likely to be married than inpatients ($p=0.002$).
• Patients’ DT scores (n=48) indicated that 40% were experiencing severe distress (score ≥7) while another 40% reported moderate distress (score 4-6)

• Two patients were unable to quantify their distress

• Inpatients reported higher levels of distress than outpatients (inpatients $M=6.7$, SD 2.1; outpatients $M=4.4$, SD 2.6)

• this difference was significant ($p=0.002$)

• Problems reported on the DT problem list by more than half the respondents:
  - fatigue (78%), pain (64%), worry (62%), sadness (56%), and sleep disturbance (54%).
Symptom “bother”: Pain (34%) and emotional experiences (32%) far outweighed other symptoms, followed by fatigue (6%), nausea (6%), and shortness of breath (6%)

Levels of distress (DT) significantly correlated with **two** QUAL-EC domains: symptom control \((r=0.52, p<0.001)\) and preparation for end of life \((r=0.32, p<0.05)\)
Feasibility

• **Time taken to complete the QUAL-EC:** Range: 3-14 minutes ($M=7$ minutes, SD 3.0 minutes)

• **Perceptions of Questions:**
  - **94% Agreed/ Strongly Agreed** that the questions were clear
  - **86% Disagreed/ Strongly Disagreed** that the questions were hard to understand
  - **74% Disagreed/ Strongly Disagreed** that the questions were hard to answer
  - **92% Disagreed/ Strongly Disagreed** that the questions were stressful
  - **90% Agreed/ Strongly Agreed** that they were glad they took part in the study
Qualitative Findings

Thematic analysis of the recorded interviews identified six major themes:

- **The health care team** (trust, multiple providers)
- **Family** (concerns for family members)
- **Approaching death** (thoughts about dying, acceptance and questioning how they would die)
- **Experiences of worry** (pervasiveness of stress of their situation)
- **Coping** (attitudes in face of disease)
- **The QUAL-EC experience** (misunderstanding Qs, positive aspects of their disease experience)
Living with cancer and its treatment brings significant and complex challenges for patients:
- 71% reported moderate to severe levels of distress (pain/HC team)
- Pain and emotional issues far outweighed other symptoms
- Fluctuating nature of symptoms require monitoring

Physical symptoms are known to cause distress and suffering in patients with advanced cancer; yet there is more to understand

Distress and preparation for EOL - QUAL-EC identified
- Focus on concerns for loved ones in the context of needing family support for coping not always addressed in other instruments

The QUAL-EC teases out often unexpected patient experiences in terms of unmet emotional and psycho-social needs

DT may best used as SCREEN; QUAL-E/EC as a means of teasing out actual sources of emotional distress


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