

Quality of Life at the End of Life:

Evaluating the Clinical Utility of the QUAL-EC in Patients with Advanced Cancer

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Introduction

- 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**

Introduction (continued)

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

* Pilot Study⁽¹⁾

- ❑ 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

¹ Wilkinson A, Slatyer S, McCullough K, Williams A. Exploring the Quality of Life at the End of Life (QUAL-E) instrument with Australian palliative care hospital patients. Journal of Palliative Care. 2014;30(1):16-23.

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.

Aims

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

(2) Lo C, Burman D, Swami N, Gagliese L, Rodin G, Zimmermann C. Validation of the QUAL-EC for assessing quality of life in patients with advanced cancer. *European Journal of Cancer*. 2011;57:554-60.

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.

Results

N=50	Demographics				
Age	60 years Mean	40 - 81 years Range			
Gender %	66 % Male	44% Female			
Diagnosis %	26% Mesothelioma	22% Lung Ca	10% Brain Ca		
Time since diagnosis	0-3 months (n=15)	6-12 months (n=12)	1-2 years (n=8)	2 - 5 years (n=9)	More than 5 (n=6)

The only significant demographic variation between participant groups was that outpatients were significantly more likely to be married than inpatients ($p=0.002$).

Levels of Distress

- 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%).

QUAL - EC Scores

Domain/Score	Mean	Standard Deviation	Correlation w/ DT
Symptom Control (possible score: 15)	10.2	2.9	r=0.52 p = < 0.001
Relationship w/ Healthcare Provider (possible score: 25)	19.3	3.3	Not significant
Preparation for End of Life (possible score: 20)	10.2	3.6	r=0.32 p = < 0.05
Life Completion (possible score: 25)	18.3	4.7	Not significant

- ❖ 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=7minutes, 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*)

Discussion- in progress

- 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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