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Development of "Quality of Care for Patients With Advanced Illnesses (QCPAI)" Instrument for Measuring the Quality of End-of-Life Care From Patients' Perspective

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AIM

To develop a comprehensive generic instrument - Quality of Care for Patients with Advanced Illnesses (QCPAI) - for measuring the quality of end-of-life (EOL) care from the patients' perspective.

METHODS

- The instrument development was carried out in 5 steps:
  - Scoping review
  - Item development
  - Translation
  - Cognitive debriefing
  - Reconciliation
- Based on a scoping review# to identify key dimensions of quality of death, 10 dimensions were identified for EOL care :
  - Safety
  - Appropriateness of care
  - Coordination and continuity of care
  - Health-related quality of life
  - Life continuity
  - Dignity
  - Empowerment
  - Hope
  - Effective interpersonal interactions and relations
  - Effective communication
- 17-item QCPAI instrument with 5 response levels (Strongly disagree to Strongly agree) was developed to capture the identified dimensions.
- Two versions of QCPAI were developed:
  - Self-administration by patients
  - Proxy-administration by family caregivers (with patient perspective)
- Both versions were translated into Chinese (with forward and backward translation).
- The initial versions were pilot tested via cognitive debriefing using semi-structured qualitative interviews with advanced cancer patients and family caregivers from Singapore.
- Feedback on the clarity and understandability of instructions, items, response categories, and coverage of the dimensions was incorporated during the reconciliation step to finalize the instrument.

RESULTS

- The initial versions of the QCPAI in English and Chinese languages were pilot tested in 12 patients and 10 family caregivers.
- Based on patients and caregivers' feedback, 4 items with overlapping concepts were removed, and 2 new items were added to cover more aspects of care.
- The final version of QCPAI has 15 items.

RESULTS (CONTINUE)

Patients	N = 12
Age, Mean (Range)	63 (40, 85)
Female, n	6
Ethnicity, n	
Chinese	10
Non-Chinese	2
Education level, n	
Primary or less	2
Secondary	6
Post-secondary	4
Cancer type, n	
Lung	4
Colon	4
Others	4

Caregivers	N = 10
Age, Mean (Range)	45 (28, 65)
Female, n	7
Ethnicity, n	
Chinese	8
Non-Chinese	2
Education level, n	
Primary or less	0
Secondary	1
Post-secondary	9
Relationship with patient	
Son/daughter	7
Spouse	3

- Final QCPAI items:

1. Healthcare workers generally asked enough questions to understand my needs.
2. Healthcare workers customized the treatments to meet my care preferences.
3. I received excellent medical care.
4. Healthcare workers generally helped to control my pain and discomfort to the desired level.
5. Waiting times were reasonable.
6. Costs were not a barrier to getting the medical care I wanted.
7. Healthcare workers generally gave clear and timely information.
8. Healthcare workers generally treated me with kindness and compassion.
9. Healthcare workers generally treated me with dignity.
10. Healthcare workers generally helped me cope emotionally.
11. Healthcare workers generally addressed my religious, spiritual, and cultural needs.
12. Healthcare workers generally did a good job coordinating my care.
13. Healthcare workers generally made it easy for me to communicate with family and friends during my in-facility care (such as in hospitals, hospices, nursing homes).
14. I was able to receive care at my places of choice (such as home, hospital, hospices, nursing homes).
15. The healthcare facilities where I received care were generally clean, safe, and comfortable.

CONCLUSIONS

- The QCPAI instrument measuring all key aspects of EOL care was developed.
- It can be self-administered by patients or family caregivers in English and Chinese languages.
- A study on evaluating the measurement properties of this instrument is ongoing.

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Bhadelia A, Oldfield LE, Cruz JL, Singh R, Finkelstein EA. Identifying Core Domains to Assess the "Quality of Death": A Scoping Review. J Pain Symptom Manage. 2022 Apr;63(4):e365-e386.