

Introduction Patients near the end of life are not always able to consent to research participation but it is important they have the opportunity to be represented. Proxies may offer a valuable perspective on the quality of end of life care. Although there is evidence that proxy responses differ, exploring why and where differences occur may help in deciding on their use in empirical studies.

Aim What is the agreement on quality of life outcome questions between patients receiving supportive care and proxy response by close persons (CPs) and healthcare professionals (HCPs)?

Methods A mixed methods study was conducted with 72 participants recruited via the hospice (33 patients, 22 CPs and 17 HCPs). Participants completed three quality of life outcome scales (ICECAP-SCM, EQ-5D-5L and ICECAP-A) during think-aloud interviews. Analysis explored difficulties and enablers for proxy completion. Constant comparison and extreme case analysis explored how CPs and HCPs completed the scales on behalf of patients.

Results Proxy responses depend on how well the proxy knows the patient but there is no clear difference between proxy roles. Choice and dignity are more accurately completed by proxies than physical or emotional suffering. This may be related to the relationship between the patient and proxy and willingness to discuss care planning preferences.

Conclusion This study has important implications for research and practice. Accurate measurements of the quality of end of life care from the patient perspective is essential, especially as the provision of 24/7 palliative care becomes the priority.

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HOW FAR CAN WE TRUST PROXY RESPONDENTS FOR PATIENTS RECEIVING SUPPORTIVE AND PALLIATIVE CARE WHO ARE UNABLE TO CONSENT TO RESEARCH?

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