

Developing a bereaved caregiver survey to capture the ALS Palliative Care experience

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BACKGROUND

Existing survey tools focus on inpatient palliative care and the nursing needs in the final days of life, which doesn't fully capture the palliative care experience for ALS patients.

METHODS



1. Modified Delphi Process with Experts
 - 2 brainstorm meetings + 2 Qualtrics surveys to refine survey items
 - Expert panel: 13 ALS and Palliative care experts
2. Pilot: 3 bereaved ALS caregivers through PFAC

RESULTS

- Domains: patient and caregiver support, communication, end of life experience
- 31-item survey (9-item demographics)
- Pilot results: survey is comprehensive, relevant, appropriate length

DISCUSSION

- This survey specifically captures the bereaved caregiver's perspective of ALS care and explores topics missing in existing survey studies around palliative care in ALS.
- Next steps: administer survey

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ALS Bereaved Caregiver Survey Domains and Questions



Patient and Caregiver Support

1. Would you say that **your loved one** received adequate treatment for their **physical symptoms**?
2. Did **your loved one** receive the **emotional support** that they needed and wanted from the healthcare team?
3. Did **you** receive the **emotional support** that they needed and wanted from the healthcare team?
4. Were **your loved one's religious, spiritual, and cultural traditions** respected and supported by the healthcare team?



Communication

1. Did **you** get the **practical help and information** you needed to arrange care for your loved one, for example, information about obtaining equipment or hiring caregivers?
2. Did **you** receive the guidance you needed to help you **prepare for what was to come** with your loved one's illness?
3. Do you believe **your loved one** received medical care that was consistent with their **values and preferences** throughout the course of their disease?
4. Palliative Care "Measuring what matters" initiative statements



End of life

1. Did **your loved one** receive the kind of care that they wanted, in the place they preferred, at the end of their life?
2. Did **you** get the support **you** needed from the healthcare team **after the death** of your loved one?



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Modified Delphi Process

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|---------|---|
| Round 1 | • Meeting: Brainstorm domains
• Follow-up survey: comments on domains and provide suggestions for questions in domains |
| Round 2 | • Meeting: Brainstorm questions
• Follow-up survey: comments on questions |
| Round 3 | • Meeting: Review and finalize survey |

PallCare: Measuring What Matters

The following statements assess the healthcare team's **quality of communication**. Would you say you *disagree, feel neutral, or agree* with the following statements?

1. I believe my loved one felt heard and understood by the care team.
2. I, as the family caregiver, felt heard and understood by the care team.
3. The care team put my loved one's best interests first when making recommendations about their care.
4. The care team saw my loved one as a person, not just someone with a medical problem.
5. The care team understood what was important to my loved one in their life

Questions on Overall Care

- As you reflect on the healthcare experience overall, what are some of the things that were **most helpful** to support either you or your loved one's **quality of life**?
- Was there anything that the healthcare team did that made things **harder** for you or your loved one?
- Overall, how would you rate the quality of care that **your loved one** received throughout their illness?
- Overall, how would you rate the support that **you** received from the healthcare team throughout your loved one's illness?
- What helped to promote your and your loved one's **quality of life**, and helped you cope, throughout the illness?
- Do you have any **advice** for other people who are facing ALS in a loved one?
- Is there anything else you would like to share?

March 2023 – Present: Administer phone survey with goal of 15 participants