The Involvement of Cancer Patients in the Four Stages of Decision-making in Continuous Sedation Until Death

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Published in:
Journal of Pain and Symptom Management

Publication date:
2018

Document Version:
Final published version

Citation for published version (APA):
Wednesday, October 3, 2018

RESEARCH FORA

RF1-A
Volunteer Involvement in the Organisation of Palliative Care: Results from a Large-scale Survey of Healthcare Organisations in Flanders and Brussels

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Objectives: Aging populations increasingly face chronic and terminal illnesses, emphasising the importance of palliative care and quality of life for terminally ill people. Facing resource constraints in professional healthcare, some governments expect informal caregivers like volunteers to assume a greater share of care provision. Volunteers are present in palliative care and perform many roles, from administration to providing companionship. However, it is unknown how involved they are in the organisation of care and how healthcare organisations appraise their involvement. To address this, we provide an extensive description of the involvement of registered volunteers in direct patient palliative care across the Flemish healthcare system in Belgium.

Method: We conducted a cross-sectional postal survey of 342 healthcare organisations in Flanders and Brussels in 2016, including full-population samples of palliative care units, palliative day care centres, palliative home care teams, medical oncology departments, sitting services, community home care services and a random sample of nursing homes. Volunteer involvement was measured using Sallnow and Paul’s power-sharing model.

Results: Response was obtained for 254 (79%) organisations. Volunteer involvement was restricted to informing and the organisation receiving feedback from volunteers. Healthcare organisations were supportive towards involvement, but dismissive towards allowing decision-rights and autonomy. Three clusters of volunteer involvement emerged: ‘strong involvement’ (31.5%), ‘restricted involvement’ (44%) and ‘uninvolved’ (24.5%). Degree of involvement was found to be positively associated with volunteer training (p<.001) and performance of practical (p<.001) and psychosocial care tasks (p<.001). Dedicated palliative care services displayed a strong degree of volunteer involvement, contrary to generalist palliative care, particularly nursing homes.

Conclusions: Results indicate there is potential for more volunteer involvement in the organisation of care. We offer practical suggestions to stimulate involvement but emphasise the need for investment in volunteer training, support and future research into the importance and potential of involvement at the volunteer level.

RF1-B
The Involvement of Cancer Patients in the Four Stages of Decision-making in Continuous Sedation Until Death

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Background: Involving patients in decision-making is considered to be particularly appropriate towards the end of life. Professional guidelines emphasize that the decision to initiate continuous sedation should be made in accordance with the wishes of the dying person and be preceded by their consent.

Aim: To describe the decision-making process preceding continuous sedation until death with particular attention to the involvement of the person who is dying.
Design: Qualitative case studies using interviews.

Setting/participants: Interviews with 26 physicians, 30 nurses and 24 relatives caring for 24 patients with cancer who received continuous sedation until death in Belgium, UK, and the Netherlands.

Results: We distinguished four stages of decision-making: initiation, information exchange, deliberation and the decision to start continuous sedation until death. There was wide variation in the role the patient had in the decision-making process. At one end of the spectrum (mostly in UK), the physician discussed the possible use of sedation with the patient, but took the decision themselves. At the other end (mostly in BE and NL), the patient initiated the conversation and the physician’s role was largely limited to evaluating if and when the medical criteria were met.

Conclusions: Decision-making about continuous sedation until death goes through four stages and the involvement of the patient in the decision-making varies. Acknowledging the potential sensitivity of raising the issue of end-of-life sedation, we recommend building into clinical practice regular opportunities to discuss the goals and preferences of the person who is dying for their future medical treatment and care.

RF1-C
Peer-facilitated Public Sessions as a Strategy to Increase Engagement in Advance Care Planning in British Columbia

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Objectives: Advance Care Planning (ACP) is a process whereby people reflect upon and share their values, beliefs and wishes for future healthcare with family, friends and healthcare providers. Knowing this information informs decision-making about the treatment and care options right for them. Despite many benefits, public awareness of, and engagement in, ACP is low in British Columbia (BC). As one approach aiming to address public ACP engagement, the BC Centre for Palliative Care partnered with community organisations from across the province to spread a community-delivered public education model; peer-facilitated public ACP sessions.

Methods: The sessions are designed to inform public participants about the ACP process, and increase their comfort and readiness to engage in ACP, including sharing with their family and healthcare providers. In these interactive sessions, trained peers educate participants about ACP and stimulate conversations using stories and personal experiences. To assess the sessions’ impact on public engagement in ACP, we collected survey data from participants at the end of sessions and 4-6 weeks later. Qualitative data was collected through focus groups and interviews to assess peer-facilitator and community organisation experience.

Results: In 40+ sessions attended by over 800 participants in 23 communities throughout BC, our results demonstrate that peers are well suited to this role; sessions were well received and effective at promoting ACP engagement. Within 4-6 weeks of attending the session almost all participants (97%) had thought about their personal values, beliefs and wishes, and two-thirds had had conversations with those close to them (a 76% increase from pre-workshop rates). There was also a 75% increase in conversations with healthcare providers, and a 69% increase in creation of ACP documents. All organisations have continued to deliver sessions demonstrating sustainability.

Conclusions: Peer-facilitated ACP sessions are an effective strategy to increase ACP awareness and engagement among British Colombians.

WORKSHOPS AND PROFFERED PAPERS

A04-B
Caring for a Child with a Complex Chronic Condition: Parent-Reported Burden and Quality of Life

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Objectives: Parents caring for children with complex chronic conditions (CCC) face higher care-giving responsibilities, which may negatively impact caregiver burden and quality of life (QOL). The primary goal of this analysis was to measure burden of illness/QOL for parents caring for a child with CCC, and to examine their association with sociodemographic characteristics.