Royal United Hospitals Bath
NHS Foundation Trust

End of Life Care
Current Awareness Bulletin

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Title: Communication between healthcare professionals and relatives of patients approaching the end-of-life: A systematic review of qualitative evidence.

Citation: Palliative Medicine; Sep 2019; vol. 33 (no. 8); p. 926-941

Author(s): Anderson, Rebecca J; Bloch, Steven; Armstrong, Megan; Stone, Patrick C; Low, Joseph TS

Background: Effective communication between healthcare professionals and relatives of patients approaching the end-of-life is vital to ensure patients have a 'good death'. To improve communication, it is important to first identify how this is currently being accomplished.

Aim: To review qualitative evidence concerning characteristics of communication about prognosis and end-of-life care between healthcare professionals and relatives of patients approaching the end-of-life.

Design: Qualitative systematic review (PROSPERO registration CRD42017065560) using thematic synthesis. Peer-reviewed, English language articles exploring the content of conversations and how participants communicated were included. No date restrictions were applied. Quality of included studies was appraised using the Joanna Briggs Institute Critical Appraisal Checklist for Qualitative Research.

Data sources: An electronic database search of CINAHL, MEDLINE, PsycINFO and EMBASE was performed.

Results: Thirty-one papers were included. Seven themes were identified: highlighting deterioration; involvement in decision-making, post-decision interactional work, tailoring, honesty and clarity, specific techniques for information delivery and roles of different healthcare professionals. Varied levels of family involvement in decision-making were reported. Healthcare professionals used strategies to aid understanding and collaborative decision-making, such as highlighting the patient's deterioration, referring to patient wishes and tailoring information delivery. Doctors were regarded as responsible for discussing prognosis and decision-making, and nurses for providing individualized care.

Conclusion: Findings suggest training could provide healthcare professionals with these strategies to improve communication. Interventions such as question prompt lists could help relatives overcome barriers to involvement in decision-making. Further research is needed to understand communication with relatives in different settings and with different healthcare professionals.

Title: Do published patient decision aids for end-of-life care address patients' decision-making needs? A systematic review and critical appraisal.

Citation: Palliative Medicine; Sep 2019; vol. 33 (no. 8); p. 985-1002

Author(s): Phillips, Georgina; Lifford, Kate; Edwards, Adrian; Poolman, Marlise; Joseph-Williams, Natalie

Background: Many decisions are made by patients in their last months of life, creating complex decision-making needs for these individuals. Identifying whether currently existing patient decision aids address the full range of these patient decision-making needs will better inform end-of-life decision support in clinical practice.

Aims and design: This systematic review aimed to (a) identify the range of patients' decision-making needs and (b) assess the extent to which patient decision aids address these needs.

Data sources: MEDLINE, PsycINFO and CINAHL electronic literature databases were searched (January 1990–January 2017), supplemented by hand-searching strategies. Eligible literature reported patient decision-making needs throughout end-of-life decision-making or were evaluations of patient decision aids. Identified decision aid content was mapped onto and assessed against all patient decision-making needs that were deemed 'addressable'.

Results: Twenty-two studies described patient needs, and seven end-of-life patient decision aids were identified. Patient needs were categorised, resulting in 48 'addressable' needs. Mapping needs to patient decision aid content showed that 17 patient needs were insufficiently addressed by current patient decision aids. The most substantial gaps included inconsistent acknowledgement, elicitation and documentation of how patient needs varied individually for the level of information provided, the extent patients wanted to participate in decision-making, and the extent they wanted their families and associated healthcare professionals to participate.

Conclusion: Patient decision-making needs are broad and varied. Currently developed patient decision aids are insufficiently addressing patient decision-making needs. Improving future end-of-life patient decision aid content through five key suggestions could improve patient-focused decision-making support at the end of life.

Title: Robotic technology for palliative and supportive care: Strengths, weaknesses, opportunities and threats.

Citation: Palliative Medicine; Sep 2019; vol. 33 (no. 8); p. 1106-1113

Author(s): Nwosu, Amara Callistus; Sturgeon, Bethany; McGlinchey, Tamsin; Goodwin, Christian DG; Behera, Ardhendu; Mason, Stephen; Stanley, Sarah; Payne, Terry R

Background: Medical robots are increasingly used for a variety of applications in healthcare. Robots have mainly been used to support surgical procedures, and for a variety of assistive uses in dementia and elderly care. To date, there has been limited debate about the potential opportunities and risks of robotics in other areas of palliative, supportive and end-of-life care.

Aim: The objective of this article is to examine the possible future impact of medical robotics on palliative, supportive care and end-of-life care. Specifically, we will discuss the strengths, weaknesses, opportunities and threats (SWOT) of this technology.

Methods: A SWOT analysis to understand the strengths, weaknesses, opportunities and threats of robotic technology in palliative and supportive care.

Results: The opportunities of robotics in palliative, supportive and end-of-life care include a number of assistive, therapeutic, social and educational uses. However, there are a number of technical, societal, economic and ethical factors which need to be considered to ensure meaningful use of this technology in palliative care.

Conclusion: Robotics could have a number of potential applications in palliative, supportive and end-of-life care. Future work should evaluate the health-related, economic, societal and ethical implications of using this technology. There is a need for collaborative research to establish use-cases and inform policy, to ensure the appropriate use (or non-use) of robots for people with serious illness.

Title: Palliative care after the Liverpool Care Pathway: a study of staff experiences.

Citation: British Journal of Nursing; Aug 2019; vol. 28 (no. 15); p. 1001-1007

Author(s): Collins, Heather; Raby, Peter

Abstract: The objective of this study was to explore nurses' perceptions of end-of-life care following the withdrawal of the Liverpool Care Pathway (LCP). Thirteen semi-structured interviews were conducted with nurses working in palliative care. Data were analysed using thematic analysis. Three themes emerged: perceptions of the LCP, prevailing issues, and patients' and families' experiences. This study suggested that the removal of the pathway has not remedied the issues attributed to it. Further, the way in which the LCP was removed indicates that the non-expert media can play a negative role in how palliative care is perceived, which inhibits the care process. In this respect it is important that 'insider' voices are also heard, in order to educate and also redress disinformation. Similarly, broader, persisting, contextual challenges facing staff need addressing in order to prevent a repeat of the issues leading to the removal of the LCP.

Title: Living, loving, dying: Insights into rural compassion.

Citation: Australian Journal of Rural Health; Aug 2019; vol. 27 (no. 4); p. 328-335

Author(s): Marsh, Pauline; Thompson, Stephanie; Mond, Jonathan

Objective: To improve understandings of the enablers and barriers to maintaining good quality of life for people dying, caring and grieving in rural areas.

Design and setting: In-depth interviews designed on participatory research principles were held with bereaved carers living in a small community in rural Tasmania. Participants had cared for someone until their death within the 3-year period prior.

Participants: Nineteen participants comprising 18 bereaved former carers and one person with a life-limiting illness, and all but four were over retirement age. Study aim: To explore experiences of end-of-life care in a rural community.

Results: Participants discussed the challenges they experienced during end-of-life caring, including transport into the city for treatment, and access to basic and specialised services. However, they also reported positive aspects of formal and informal palliative care, and described experiences of personable, expert, flexible and innovative caregiving.

Conclusions: The rural location enabled personalised and innovative expressions of care. This research adds new insight into rural end-of-life palliation, as a complex intersection of supererogation, innovation and place-driven care.

Title: Rural palliative care to support dying at home can be realised; experiences of family members and nurses with a new model of care.

Citation: Australian Journal of Rural Health; Aug 2019; vol. 27 (no. 4); p. 336-343

Author(s): Spelten, Evelien; Timmis, Jenny; Heald, Simone; Duijts, Saskia F. A.

Objective: While 60%-70% of people would prefer to die at home, only 14% do so. Families in a rural environment feel particularly unsupported in fulfilling this last wish of their loved one, which reflects the general shortage of health care workforce and resource allocation to institutions. The aim of this study was to describe the experience of families and nurses with extended rural palliative care to support dying at home.

Design: Semistructured interviews were conducted with family members and nurses. Process data were included to describe the frequency and nature of contacts. The results were analysed using descriptive analysis.

Settings: A rural town in Northern Victoria, Australia (Australian Statistical Geography Standard-Remoteness Area).

Participants: Ten family members and four nurses were interviewed.

Main outcome measures: Experience with the extended palliative care service and with the dying at home process.

Results: All patients in the project died at home. The families were very positive about the extended palliative care; it increased their familiarity with dying, and had a positive impact on bereavement. The nurses were equally positive, but also commented on the need to debrief and on the heavy emotional toll the work takes.

Conclusions: Rural care support for dying at home can be realised. This study has demonstrated the positive impact of an end-of-life service, while at the same time pointing to concerns of the nursing staff on the suitability of the model of care. Health care workers and communities alike need to be educated and have conversations on end-of-life care.

Title: Documentation of Palliative and End-of-Life Care Process Measures Among Young Adults Who Died of Cancer: A Natural Language Processing Approach.

Citation: Journal of adolescent and young adult oncology; Aug 2019

Author(s): Poort, Hanneke; Zupanc, Sophia N; Leiter, Richard E; Wright, Alexi A; Lindvall, Charlotta

Abstract: Few studies have investigated palliative and end-of-life care processes among young adults (YAs), aged 18-34 years, who died of cancer. This retrospective study used a natural language processing algorithm to identify documentation and timing of four process measures in YA cancer decedents' medical records: palliative care involvement, discussions of goals of care, code status, and hospice. Among 2878 YAs, 138 had a recorded date of death. In this group, 54.3% had at least one process measure documented early (31-180 days before death), 18.0% had only late documentation of process measures (0-30 days), and 27.5% had none documented.

Title: Do caregiver experiences shape end-of life care perceptions? Burden, benefits, and care quality assessment.

Citation: Journal of pain and symptom management; Aug 2019

Author(s): Luth, Elizabeth A; Pristavec, Teja

Context: Researchers, hospices, and government agencies administer standardized questionnaires to caregivers for assessing end-of-life care quality. Caregiving experiences may influence end-of-life care quality reports, which have implications for caregiver outcomes, and are a clinical and policy priority.

Objectives: This study aims to determine whether and how caregivers' end-of-life care assessments depend on their burden and benefit perceptions.

Methods: This study analyzes data from 391 caregivers in the 2011 National Study of Caregiving and their Medicare beneficiary care recipients from the 2011-2016 National Health and Aging Trends Study. Caregivers assessed five end-of-life care aspects for decedents. Logistic regression was used and predicted probabilities of caregivers positively or negatively assessing end-of-life care based on their burden and benefit experiences calculated. Analyses adjusted for caregiver and care recipient demographic and health characteristics.

Results: No or minimal caregiving burden is associated with ≥0.70 probability of caregivers reporting they were always informed about the recipient's condition and that the dying person's care needs were always met, regardless of perceived benefits. High perceived caregiving benefit is associated with ≥0.80 probability of giving such reports, even when perceiving high burden.

Conclusion: Caregiver burden and benefit operate alongside one another regarding two end-of-life care evaluations, even when years elapse between caregiver experience reports and care recipient death. This suggests that caregiver interventions reducing burden and bolstering benefits may have a positive and lasting impact on end-of-life care assessments.

Title: Body Perception and Organ Donation: Bereaved Parents' Perspectives.

Citation: Qualitative Health Research; Sep 2019; vol. 29 (no. 11); p. 1623-1633

Author(s): Mahat-Shamir, Michal; Hamama-Raz, Yaira; Leichtentritt, Ronit D.

Abstract: The view of the body in sociological, psychological, and gender studies may be broadly summarized to three metaphors: (a) the body as a machine, (b) the body as Self, and (c) the body as sacred and sanctified entity. Each of these philosophical views has an impact on organ donation. The current study aimed at revealing body perception of bereaved Israeli parents who agreed to donate organs of their deceased child. A deductive and inductive thematic analysis captured an ongoing perceptual change that bereaved donor parents experienced in their view of the child's body. Parents' ability to move between two positions (the body as Self, the body as a machine) allowed them to agree with and protect their decision to donate as well as to maintain an ongoing bond with their deceased child. The view of the body as scared entity was not evident in the bereaved parents' narratives.

Title: Attitudes and beliefs regarding organ donation among South Asian people in the UK.

Citation: Journal of Kidney Care; Jul 2019; vol. 4 (no. 4); p. 184-198

Author(s): Pradeep, Agimol; Ormandy, Paula; Augustine, Titus; Randhawa, Gurch; Whitling, Mark

Abstract: There is an acute shortage of organ donors in the UK, specifically among South Asian communities. This article reports the findings from the largest ever study undertaken among South Asian people in the UK that seeks to explore attitudes and beliefs towards organ donation. This article highlights that seemingly intractable factors, such as religion and culture, are often tied to more complex issues, such as distrust in the medical system and lack of awareness, that contribute to the shortage of organ donors among South Asian communities in the UK

Sources Used:

The following databases are searched on a regular basis in the development of this bulletin: British Nursing Index, Cinahl, Medline along with a number of other sources

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