O3_A2_A_Scientific Evidence

MAPPING PATIENT'S NETWORK

Q1	**Is beneficial for terminally ill patients to involve general practitioner in an integrated palliative care model?**
Patients	Patients elderly and/or frail and/or end of life indications in a palliative facility Frail, aged, end of life adults Children in a palliative facility
Intervention	Involving GPs in palliative care
Comparator	Standard care
Outcome	Core outcome measures: **Quality of life** **Symptom burden**
Methodology	Systematic reviews Randomized controlled trials Cohort studies Registry studies
Extra	Planned subgroup analysis

Studies:
A systematic review was included (No studies= 17, N=2.434)

Indications:

1. Engaging the GPs in palliative care with relevant specialized secondary services is effective and provides positive outcomes for the patients: pain management, symptom control and functional status (1).

- Shared care were both effective in reducing hospitalisations and in significantly ($p<0.05$) reducing the length of hospital stay.
- GP engagement in the integration of primary and secondary services in the provision of palliative care, studies showed a significant dencrease in number of hospital admissions ($p=0.0069$; $p=0.001$).
- Performance status was measured via self-report surveys, significant improvement ($p=0.015$) accrued for those receiving integrated care.
- **Quantitative studies showed no measured improvement in quality of life or symptom burden.**
- Survey of GPs also found improved pain management, symptom control and increased security for patient and family.

Comments:
It requires an effective communication between the GP and the specialist secondary service (1). Although, the long-term sustainability of an integrated approach to palliative care provision between primary and secondary care has yet to be investigated.

Conclusions:
No measured improvement in quality of life or symptom burden.

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References:

1. Carmont S, Mitchell G, Senior H, Foster M. Systematic review of the effectiveness, barriers and facilitators to general practitioner engagement with specialist secondary services in integrated palliative care. BMJ Supportive & Palliative Care 2017; 0:1–15.

Q2	**Does decision making for end of life assistance should be done alone or with family support?**
Patients	Patients elderly and/or frail and/or end of life indications in a palliative facility Frail, aged, end of life adults Children in a palliative facility
Intervention	Shared decision making
Comparator	Alone decisions
Outcome	Core outcome measures: The effects of SDM intervention QOL
Methodology	Systematic reviews Randomized controlled trials Cohort studies Registry studies
Extra	Planned subgroup analysis Children

Comments

Courts have found that competent adults have the right to refuse or discontinue medical interventions. For incompetent adults and children, decisions are made by a surrogate. In the absence of an advance directive or documentation of goals of care, the surrogate, in collaboration with the medical team, determines a plan of care, including decisions about end-of-life care. When issues of medical futility occur, attempts to work with patients and their families should be undertaken, but if the dispute cannot be resolved, a transfer in care may be the only option. (Crit Care Nurse **October 2011,** vol. 31 no. 5 **64-69).**

Studies:

- One systematic review was included (No of studies= 10, N= 438)
- One systematic review was included ((no 17 – 6 with cancer, n=688)
- 2 Observational studies (N= 43, and n=436)

Indications:

1. The presence of family members at the time of death when compared to patients who died alone is an indicator for greater presence of do not resuscitate (DNR) orders, documentation of withdrawn treatments, and use of pain medication prior to death (1).
2. Family involvement increases the use of comfort care within the hospital for dying patients, also implying that family members play a role in making these decisions (1,4).

Erasmus+

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3. In paediatric oncology the decision to start a particular treatment does not leave much room for deliberation, which may explain the finding that although treatment is discussed, treatment-related decisions are usually not discussed (2). Studies that helped children to participate in decision-making with parents and healthcare staff were not found (2).
4. Companion/family involvement is only reported in small number of eligible decision aids articles (6 studies from the systematic review). As family presence in medical consultations is associated with clinician's enhanced willingness to provide additional biomedical information, similar benefits may derive from the inclusion of a companion in the decision at the EOL (6).

Comments:

- The support instructions or structure of the decision-making process were missing in half the studies (6).
- Promoting excellent communication between physicians and family members is one way to lessen caregiving burdens. Group decision making among a family was preferred over use of an individual surrogate, indicating the need for communication between family members. pen family communication was found to be an indicator for improved congruence in care preferences between terminally ill patients and their caregivers (1).
- Several randomized controlled studies found that participants in the intervention group had statistically significantly reduced state anxiety scores after receiving the prospective social skills training intervention in addition to normal school reintegration (5).
- Given the sensitivities of end-of-life, self-administered DAs are inappropriate in this context and genuine informed decision-making cannot happen while those gaps in the usual care remain (6).

Conclusions: Shared decision making at the end of life are generally acceptable by users, and appear to increase knowledge and reduce decisional conflict but this effectiveness is mainly based on low-level evidence (6).

References:

1. Wallace C et al. Family communication and decision making at the end of life: A literature review. Palliative and Supportive Care (2015), 13, 815–825.
2. Wiedering B, Noordman J, Tates Kiek, Zwaanswijk, Elwyn G, De Bont E, Beishuizen et al. Sharing decisions during diagnostic consultations; an observational study in pediatric oncology. Patients Education and Counselling 99 (2016): 61-67.
3. Ranmal R,Prictor M,Scott JT. Interventions for improving communication with children and adolescents about their cancer (Review) !!!
4. Xiaoli Gu End-of-life decision-making of terminally ill cancer patients in a tertiary cancer center in Shanghai, China Support Care Cancer (2016) 24:2209–2215
5. Ranmal R,Interventions for improving communication with children and adolescents about their cancer (Review), Cochrane Database of Systematic Reviews 2008, Issue 4. Art. No.: CD002969.
6. Magnolia Cardona-Morrella ,A systematic review of effectiveness of decision aids to assist older patients at the end of life, Patient Educ Couns. 2016 Oct 11. pii: S0738-3991(16)30457-

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