

Person centered end-of-life care: a Transmural Care Pathway

JMM Meijers^{1,3}, L Dijkstra², L Hollanders³, C de Weerd-Spaetgens³, W Domincus⁴, E Knapen³, AB Wichmann⁵, AS Groenewoud⁵

1 Maastricht University, Maastricht, The Netherlands

2 MCC OMNES, Sittard, The Netherlands

3 Zuyderland Medical Center, Sittard, The Netherlands

4 Medical Centre Sittard Oost, The Netherlands

5 IQ healthcare, Radboud University Medical Center, Nijmegen, The Netherlands

Introduction

Currently, the quality of palliative care is considered as suboptimal. The main reason for this is the reactive character of current palliative care: there is late identification of palliative patients, moderate symptom control and insufficient awareness of the patient needs and wishes. Moreover, palliative patients often have multiple problems within the physical, psychological, functional and social domain. This requires multidisciplinary collaboration between intra- and extramural health care professionals. The aim of this research project is to develop and evaluate (process and effect) a transmural palliative care pathway (TMZP). The pathway is built upon seven elements (see figure 1).

Figure 1: Flowchart palliative care path



Methods

The TMZP is pilot tested by 15 GPs, 10 specialists (oncologists and geriatricians) and 9 pharmacists in the Netherlands. The TMZP will be continuously evaluated from December 2015 until September 2017. The TMZP process will be evaluated by means of interviews with relatives of diseased, and focus groups with GPs, medical specialists and coordinators of the TMZP. After each evaluation, findings will be shared with the TMZP project group so process issues can be constantly optimized (action research). The effects of the TMZP are measured cross-sectional (through questionnaires, focus groups and interviews with relatives) by using an intervention group (TMZP) and a control-group (care as usual). Data will be collected on care burden for relatives, health care usage, place of death and quality of dying.

Results

Results are preliminary (60 patients are included in the TMZP).

Process measures still identify late inclusion; patients die within 6 month after inclusion. Medical specialists and GPs find it hard to communicate about end-of-life in an earlier phase. Although due to communication training they are feeling more confident. Although mentioned barriers, the majority of the health care professionals is positive about the TMZP and find it a useful innovation that will lead to a higher quality of care. Another barrier was the perceived administrative burden of the pathway. Together with GPs and specialists we are currently implementing a digital communication platform for patients and caregivers, which is also suitable for continuous outcome monitoring.

Effects (outcomes and costs): Preliminary data indicate in the direction of 1) better experienced quality of dying (patients accepted impending death and were at peace); 2) more patients die at their usual place of residence instead of in the hospital; 3) proactive inclusion in the pathway, and anticipation on approaching death by GPs; 4) bearable burden for informal care givers; 5) good quality of care as reported by informal caregivers, through the patient's eye; 6) more intense communication between GPs and medical specialists and with patients.

Conclusion

Overall, the TMZP is evaluated as a positive innovation that increases awareness about the palliative care phase, end of life communication and specific care needs. End of life communication is still difficult in medical specialists and GPs due to a more 'cure' way of thinking.