

PALLIATIVE TERMINAL CARE AT HOME: THE FAMILY CARER'S VULNERABILITY

IM Proot^{abc}, H Huijer Abu-Saad^a, M Goldsteen^c, GAM Widdershoven^c

^a Centre for Nursing Research, ^b Institute for Bioethics, ^c Department of Health Ethics and Philosophy, Maastricht University, Maastricht, The Netherlands.

Aim: The study explored the needs and experiences of terminally ill patients and their family carers at home. The presentation will focus on the results of the family carer interviews.

Method: Semi-structured interviews are held with terminally ill patients (with a life expectancy of 3 months or less) in the home situation (N=13), their family carers (N=13), and providers (N=13); and with bereaved carers (N=14). The study was conducted in Limburg, the Netherlands. Interview questions include 1) the most salient health problems that patients and family carers encounter, 2) the needs of patients and family carers for home care, and 3) the extent that home health services meet these needs. Data have been analysed using the procedures and principles of grounded theory.

Results: Caring for terminally ill patients at home requires continuous balancing between care burden and capacity to cope, and triggers the vulnerability of the family carer. In the family carer interviews the core category 'vulnerability' and different factors impacting on the carer's vulnerability were identified. Care burden, constrained own activities, fear, insecurity, loneliness, facing death and lack of support may increase vulnerability, and may be risk factors for fatigue and burnout. Continued own activities, hope, keeping control, satisfaction and support may decrease vulnerability, and may protect against fatigue and burnout.

Discussion & Conclusions: Supporting and instructing families, providing aids to facilitate daily care, and informing families are issues that need the providers' attention and further study, as are stimulating families to keep control and to maintain own activities and social contacts.