A support group programme for family members: an intervention during ongoing palliative care

av

Anette Henriksson

Akademisk avhandling

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Opponent: Professor Anna-Karin Edberg
Lunds universitet

Örebro universitet
Institutionen för hälsovetenskap och medicin

70182 Örebro
Abstract


Family members are central in providing care for patients with life-threatening illness, but they often experience a lack of necessary preparation and knowledge, with a need for information and psychosocial support. The overall aim of this thesis was to investigate participant’s experiences as well as effects of a support group programme for family members of patients with life-threatening illness during ongoing palliative care. Methods: A mixed method design was used. Study I was retrospective descriptive and used a phenomenological method to analyse 10 face-to-face interviews about experiences of participating in the programme. Study II was retrospective descriptive and used qualitative content analysis to analyse 29 telephone interviews about experiences of the programme design. Study III was correlational and used a confirmatory factor analysis to psychometrically evaluate the preparedness for caregiving scale (PCS), caregiver competence scale (CCS) and rewards of caregiving scale (RCS) in 124 family members. Study IV was prospective quasi-experimental and used inferential statistics to investigate effects of the programme, assessing preparedness, competence, rewards, anxiety, depression, hope and health in 125 family members. Results: The main experiences of participation in the programme were; a sense of safety and belonging, confirmation, insight into the gravity of the illness, and a moment of rest. The programme was experienced as covering topics of interest, structured to make participants feel invited by the caring team and using an open approach that fostered a warm atmosphere. The Swedish versions of PCS, CCS and RCS were shown to be valid and reliable. Family members who participated in the programme significantly increased in preparedness, competence and rewards in relation to caregiving. No significant changes were shown for anxiety, depression, hope and health. Clinical implications: The results should provide encouragement in the challenging work to develop and deliverer interventions, with the explicit purpose of supporting family members in palliative care.

Keywords: competence, family members, interventions, palliative care, preparedness, rewards, support groups.

Anette Henriksson School of Health and Medical Sciences Örebro University, SE-701 82 Örebro, Sweden, anette.he@telia.com