Spousal caregivers’ experiences of participation in everyday life when using respite care

Spousal caregivers play an important role to elderly persons’ aging in place. Their situation is often challenging and the couples need adequate support such as overnight respite care service. However, the use of this service is not uncomplicated to spousal caregivers and more knowledge is needed about their experiences. Therefore, the aim was to explore and describe how spousal caregivers experience and discuss participation in everyday life when using respite care.

Data collection included 12 spousal caregivers divided into three focus groups. Data were generated on two or three occasions with each group. A grounded theory approach was used during data generation and analysis.

The participants described the complexity and ambiguity of both living together and apart from each other. Everyday activities together were energy consuming and demanded constant attention to their partner’s needs. This life situation created a need for having one’s own time, yet this involved feelings of guilt and frustration. Furthermore, support from their social networks and society was important but still unsatisfactory and in order to really benefit from respite care service, mutual advantage was a prerequisite.

Independently of context should support interventions focus both on the spouses and their partners as their life situations are closely united. As a result to this study, it is suggested that spousal caregivers are assigned a more forefront position alongside of their partners when planning supportive interventions for elderly persons’ participation in everyday life.