

QUALITY OF LIFE AMONGST CAREGIVERS OF DEPENDENT OLDER PEOPLE AFFECTED BY INCONTINENCE

Hypothesis / aims of study

The aim of this study was to investigate the impact that incontinence care has on the quality of life of family caregivers of dependent older relative affected by incontinence and the specificities of incontinence care compared to other care tasks.

Study design, materials and methods

Four countries are participating in the study: Italy, the Netherlands, Slovakia and Sweden. It is a qualitative study where caregivers are interviewed about their experiences of incontinence care. A semi-structured interview analyzed with content analysis was used.

Results

Forty-eight caregivers were interviewed (see Tables 1,2). The main reason for taking over the caring role was love, a natural extension of a long relationship, a sense of duty, and to enable their relatives to stay at home despite of morbidity. It was difficult for most carers to distinguish the incontinence care from the rest of their caring tasks. They talked about the caring situation as a whole and, besides the incontinence care, they provided help with personal hygiene and running the entire household. Some caregivers experienced no problem with the incontinence task and considered it to be "part and parcel" of their work, whilst others described it as extremely difficult, interfering with their role as a partner. They commonly described that the care had impacted on their social life, with a lack of freedom due to the responsibility of assisting their relative but also due to the fatigue. Some of them suffered from physical disturbs and felt exhausted, were sad and cried during the interview. In some countries the caregivers also mentioned economic difficulties, due to the cost of incontinence aids and neglecting their job because of the caring commitments.

Interpretation of results

Many family caregivers experience an extreme burden when taking the primary care and responsibility for their relatives. Incontinence care is for some a normal part of their caring role, however for some it is a difficult task to handle. Overall the caregivers described a sense of social isolation and lack of freedom, and they expressed the desire to have a little 'time for themselves'.

Concluding message

Globally the numbers of older people within the general population are increasing round the world. Whilst the majority of the older people are relatively healthy, there are nevertheless ranges of health problems that increase in conjunction with advanced age. Many older remain living at home, despite the fact that several are in need of nursing care. Thus, it is frequently family members that provide the care and support of their elder relatives'. Incontinence (urinary as well as faecal) is a problem associated with advanced age and morbidity. This is for many people a taboo and laden subject, emotions also highlighted by the caregivers who experience an extreme burden. It is important to give the caregivers opportunity to talk openly with someone skilled and understanding about his or her situation together with the opportunity to have respite care of good quality. Caregivers' efforts and situation must be made more visible.

Table 1. Description of the caregivers

	Italy n=13	Slovakia n=17	Sweden n=9	Netherlands n=9
Gender	%	%	%	%
Male	0	30	20	33
Female	100	70	80	67
Age				
mean	57	59	78	67
Relation				
Married/live togeth	92	82	89	89
Single	8	18	11	11
Employment status				
Employed full time	31	6	0	0
Employed part time	0	6	0	44
Self employed	8	12	0	0
Housewife/husband	15	0	0	22
Retired	23	47	100	33

Volunteer worker	8	0	0	0
Unemployed	8	6	0	0
Other	8	24	0	0

Table 2. Description of the cared for's persons

	Italy n=13	Slovakia n=17	Sweden n=9	Netherlands n=9
	%	%	%	%
Gender				
Male	23	35	89	44
Female	77	65	11	56
Age				
mean	84	77	84	80
Memory/cognitive probl.				
Low	15	35	22	11
Severe	62	53	22	89

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<i>Is this a clinical trial?</i>	No
<i>What were the subjects in the study?</i>	HUMAN
<i>Was this study approved by an ethics committee?</i>	Yes
<i>Specify Name of Ethics Committee</i>	Reginal medical etics committee, Uppsala Sweden
<i>Was the Declaration of Helsinki followed?</i>	Yes
<i>Was informed consent obtained from the patients?</i>	Yes