

The carer careers of son and daughter primary carers of their very old parents in Norway

TOR INGE ROMOREN*

ABSTRACT

The purpose of this article is to analyse with longitudinal data from Norway the caring activities of sons and daughters who were the primary care-giver to a parent aged 80 or more years. The study sample consists of the 227 offspring care-givers in the Larvik study, which examined the illnesses and disabilities and the informal and formal care received until their deaths of all those aged 80 or more years in the town's population in 1981. Prospective and retrospective data were collected from that year about the health, functional losses and formal service utilisation of the older people. After the death of an older person in the study, the next-of-kin was interviewed about the informal care provided by relatives and friends during the same time span. The sequences and content of the care-giving activities differed little for son or daughter care-givers, except during a short escalation phase. The average duration of informal home care was shorter for sons than for daughters, primarily because a minority of the daughters had very long care-giving careers. The duration of the care recipients' stays in acute or long-term care institutions before death did not differ by the gender of the carer. Compared with many earlier studies, few gender differences in offspring care-giving activities were found. The findings suggest that the potential of sons to provide informal care to frail older parents is underestimated in modern societies.

KEY WORDS – care-giving careers, stages of care-giving, sons, daughters, care duration, gender differences.

Introduction

After spouses, adult children are the most frequent care-givers to older people (Chappell 1990; Qureshi and Walker 1989). As the age of care recipients increases, the proportion of care-giving spouses decreases and the proportion of care-giving children increases. Among the 'oldest old', offspring form the largest primary care-giving group. Compared to the

* Norwegian Social Research (NOVA), Oslo.

vast research literature on care-giving daughters, there are few publications on sons or which compare the two groups (Stephens and Franks 1999). Many of the main contributions are dated, and most that have compared sons and daughters have concentrated on involvement. Some have examined stress, but few have focused on task performance, the subject of this paper.

Previous research has found that daughters far outnumber sons as primary care-givers to elderly parents (Quereshi and Walker 1989; Coward and Dwyer 1990; Lee, Dwyer and Coward 1993) and are more susceptible to care-giving stress (Horowitz 1985; Coward and Dwyer 1990; Jansson, Grafström and Winblad 1997). Daughters have been found to perform more household tasks, and sons seldom to provide personal care (Horowitz 1985; Montgomery and Kamo 1989; Stoller 1990). Some studies report that as an older person becomes more dependent, there is a tendency for sons to withdraw from care-giving and to leave the work to female care-givers. Montgomery and Kamo (1989) maintained that sons abdicate the care-giving role if the parent's need for care increases.

Some researchers are however sceptical about this negative picture of sons as care-givers. Chappell (1990), for instance, has noted that the paucity of data permitted simplistic generalisations to prevail. In their study of male care-givers, Kaye and Applegate (1990) maintained that the field was rife with stereotypes, a view also expressed by Bengtson *et al.* (1995) and supported by Harris's (1998) study of sons who cared for parents with Alzheimer's disease. Merrill's (1997) study of offspring who cared for elderly parents in the United States, and van Groenou and Knipscheer's (1999) in The Netherlands, both found a more diverse picture than had been generally described. Lingsom (1991), using Norwegian national survey data, also found that sons lived closer to and had more frequent contacts with their parents than daughters. This evidence presents a more complex picture that may reflect national, cultural, cohort or period differences.

The purpose of this article is to analyse the performance by son and daughter primary care-givers of care-giving tasks to frail parents aged 80 and more years. The similarities and differences in daughters' and sons' care-giving are elucidated using the framework of a care-giving career, that is, the content, sequence and duration of the tasks of a primary care-giver from their onset until the death of the older person. Several linked research questions about the care-giving of sons and daughters are addressed. Do their care-giving careers follow the same sequence of phases? Do they perform similar or different activities in each phase? Are there differences in the phase and aggregate durations? Does the duration of informal home care influence the length of institutional care, and does this relationship differ for sons and daughters?

The paper examines these questions by studying a sample from Norway, a country that exemplifies the traditional Scandinavian model of welfare. Almost all of the country's formal health and older people's care services are tax-financed and provided by public agencies. There has also been an increasing commitment to gender equality since the 1970s, and Norway's consistently high ranking on the 'Gender empowerment measure' of the United Nations *Human Development Report* (UNDP 2002) indicates that this policy has had a positive effect. The country's distinctive welfare and gender policies suggest that its patterns of informal care-giving may differ from those to be found elsewhere.

Methods

Study population

This paper reports an analysis of data from the Larvik study of 434 people aged 80 or more years who were born before 1902, and living at home or in an institution in January 1981. Larvik is a town on the southern coast of Norway, two hours from the capital city of Oslo, and in 1981 it had 8,200 inhabitants. The study's aim was to examine the illnesses and disabilities and the informal and formal care received by the subjects up to their deaths. The last member of the main study sample died in September 1999, and no participant was lost for any other reason. The analysis reported here has examined all the offspring care-givers of the people in the main sample. The town's formal services comprised a hospital, a nursing home, a home for old people, and home help and home nursing services. All were and are run by the local authority. In addition, private general practitioners are contracted to the local authority. There are co-payments or charges for GP visits, for stays in long-term care institutions, and for home help.

Data sources

Two sets of data have been examined: (1) the responses to personal interviews with the next-of-kin after the death of the elderly person: in 95 per cent of cases the respondents were son or daughter primary care-givers; and (2) medical and nursing records, as from hospitals, nursing homes, homes for older people and home nursing services. The latter were available for all cases, and covered long-term disabilities and dementia before 1981. They were updated annually from 1981 until the death of the elderly person. The person most recently listed as next-of-kin was contacted for an interview. For the few who died without any contact with formal services, the next-of-kin was identified by asking neighbours. Interviews were

conducted in the informant's home by two nurses experienced in geriatric home care. A register card with key details of formal service contacts was compiled to guide the interviewers and to act as a check on the reliability of the care-giver's information.

Most of the data used in the following analyses were given in retrospective accounts from the older person's next-of-kin. The interview data were supported and verified by the formal care services' operational data. The pattern of health and formal service use by the study population was known to the interviewer before they met the son or daughter who had been the principal carer. Discrepancies between the two sources were extremely rare, which indicates the reliability of the retrospective data.

Partly by constructing a genogram for up to four generations, the interviews covered many of the circumstances of the older person including: occupation, marital history, health and functional losses, their use of formal services, and the content, frequency and duration of all contacts, help or care received from informal sources. The interviews also collected information about informal care-giving before 1981, so the entire career of the care-giver was covered. In addition, detailed data on the occupation, marital history, place of residence and health of the primary care-giver and his or her nuclear family members were collected. The care-giving activities (if any) of every person in the genogram, and of close friends and neighbours, were also sought.

The primary care-giver role: criteria and phases

To determine the identity of the primary care-giver, the interviewers determined who had carried out the most time-consuming tasks most often and for the longest periods. The person responsible for the greatest part of the informal care received by the older person was taken to be the primary care-giver. Other persons in the network of helpers were designated as secondary care-givers. In 79 per cent of the cases, the next-of-kin informant turned out to be the primary care-giver. Using an elaboration of Pearlin and colleagues' 'stages of role enactment' (Aneshensel *et al.* 1995: 23), the care-giving career was divided into three stages or phases: being the main supporter, of escalating care requirements, and following the parent's admission to an institution. Home care was divided into the 'main support' and 'escalation' phases to represent a marked change in the care-giving task.

The main support phase. Before the main support phase, an older person is independent, and the relationship between the primary care-giver and the care recipient has the character of normal, everyday interaction. The main support phase is the first phase of actual care-giving and begins

when, because of illness or frailty, the care recipient starts to receive permanent support from an informal care-giver.

The escalation phase. If there is a *permanent* increase in the requirement for informal care while the old person is still living at home, the care recipient enters the escalation phase of the care-giving career. This may involve a change from one type of care to more demanding tasks, or a substantial increase in the frequency of the care without a change in content. In most cases there is a clear jump; in some a gradual transition. In principle, there may be more than one transition to more demanding care, but for simplicity only the first is recognised in the career model. A scaling down of the care provided may also occur, but these are rarely permanent. There were commonly many transitory ups and downs during the main support phase before the transition to the escalation or institutional phases. The same applied to the escalation phase: fluctuations occurred until the care recipient was transferred permanently to an institution or died at home.

The institutional phase. During the main support phase or escalation phases, the care recipient may stay in an acute or a long-term care institution. But as long as the patient returns home, these incidents are considered as part of the main support or escalation phases. If the relative does not return, the admission marks the transition to the institutional phase of informal care-giving, the continuing care provision during the care recipients' last stay in an acute or long-term care institution (see Moss *et al.* 1993; Aneshensel *et al.* 1995; Tobin 1995; Lingsom 1997).

The three phases occur in different combinations for different individuals, and a single career may contain one, two or all three phases. A carer of a person with stroke, for example, could first give care at home (main support phase). Later, the care recipient may deteriorate through another illness, when care-giving changes permanently in content or frequency (escalation phase). Finally, the relative may be admitted as a permanent resident of a nursing home, beginning the institutional phase. Another common sequence is for a care-giver to be continuously engaged in a consistent set of informal care tasks until an acute illness leads to hospitalisation followed by nursing home admission: only the main support and institutional phases occur. A third common sequence occurs when a parent who had been independent has an acute fatal illness and dies in hospital: the care-giving career only involves the institutionalisation phase.

Care-giving activities

The three types of care-giving activities identified in this study are contacts, providing practical help, and providing personal care. *Contacts* refer

to being available for the old person, or actively engaging in permanent and committed contacts that the care-giver differentiates from those of a reciprocal family relationship. These kinds of contacts manifest what in everyday speech is called 'being concerned about' the person, and are a fundamental component of all that is expressed by 'care'.

Practical help was defined as help with the instrumental activities of daily life (IADL) such as housework, shopping, transport, preparation of meals, keeping a check on medicines, banking and household maintenance or, roughly speaking, household tasks. Checking on an older person, for example by 'popping in' regularly to make sure that nothing is wrong, as a care-giver might do in the case of someone with mild dementia, is also treated as practical help.

Personal care was defined as assisting with indoor mobility or with one or more activities of daily living (ADL), namely dressing, bathing, transferring from bed to chair, toileting and eating, and as watching over a person suffering from moderate or serious dementia. The majority of persons with dementia will sooner or later show loss of ADL functions. Regardless of the care recipient's ADL status or the extent of the care-giving work, in the following analyses providing care for a person with moderate or serious dementia was defined as personal care (other studies define 'personal care' differently).

Contacts, practical help and personal care successively imply an increasing load of caring work. Personal care is usually accompanied by both practical help and contacts, while practical help usually involves contacts. In the following analyses, it is assumed that care-giving activities accumulated in this way, but only the most extensive activity in each phase was measured and analysed. Thus, whenever personal care was provided, it was the only care-giving activity that was measured. Similarly, when the care recipient received practical care but not personal care, only practical care was measured.

Results

Profiles of the care recipients

The study sample of older people in the Larvik study comprised 309 women (71 %) and 125 men (29 %). There were 227 people in the sub-sample with sons or daughters who were the primary care-givers. The parents' mean ages in 1981 were 83.4 years for women and 83.6 years for men, and their mean ages of death were 90.0 years for women and 89.1 years for men.¹ Most of the study sample had a working class background, either by their own occupation or (for most women) by their husband's: 54 per cent

TABLE I. Indicators of the life situation of care-giving sons and daughters

Attribute	%		Significance of statistical test p^1
	Sons	Daughters	
Marital status: ²			
Married	80	69	
Widowed	3	20	< 0.01
Unmarried	10	7	
Divorced	7	4	
Job situation during the care-giving career:			
Employed full time	97	44	< 0.001
Employed part time	0	25	
Not in paid employment	3	32	
Living with care recipient	23	37	< 0.05
No secondary care-givers	9	28	< 0.01
Extensive help from a secondary care-giver	53	18	< 0.001
Care recipient had additional formal home help	68	71	n.s.
Average duration of home help (years)	5.2	5.4	n.s.
Care recipient had additional formal home nursing	50	55	n.s.
Average duration of home nursing (years)	0.6	0.6	n.s.
Sample size	78	149	

Notes: 1. Chi-squared test of independence for categorical variables; Analysis of variance for continuous variables. 2. At the time of the interview, *i.e.* after the period of care-giving.

had been unskilled or skilled manual workers or craftspeople with only basic education (seven years at school).

The most prevalent primary care-givers were daughters (36%), sons (19%), spouses (9%), sisters (8%), nieces (7%), daughters-in-law (6%), and nephews (4%). Only four people (1%) had no informal care-giver. If the childless are excluded, 74 per cent of the sample had a child as the primary care-giver. Of the 227 offspring primary care-givers, 140 (66%) were daughters and 78 (34%) were sons. The mean age of the care-givers at the death of their parent was 60 years for both daughters and sons.² Some 73 per cent of the son care-givers and 79 per cent of the daughters cared for their mother, so there is little evidence of gender matching between care recipients and givers. The primary care-giver was the same person through all phases of the career except in one case. It involved a daughter who was the initial primary carer of her mother with dementia, but her husband could not stand living in the same house, and the primary responsibility was passed to a sister. Table 1 presents other circumstances of the care-giving sons and daughters and details of the care that they provided.

A larger percentage of daughters than sons had been widowed, and relatively more daughters lived with the older person. Fourteen of the co-resident sons (61%) and 23 of the co-resident daughters (62%) had lived

TABLE 2. *Experience of successive phases of the care-giving career for sons and daughters*

Carer-career stage	%	
	Sons	Daughters
Main support	100	100
Escalation	36	39
Institutional (long-term care)	81	81
Institutional (hospitalisation)	13	12
No institutional phase	6	7
Sample size	78	149

with their parents throughout their lives, even after marriage. Nearly all the sons but fewer than half the daughters were employed full time. On the other hand, sons were much less likely to be the sole providers of informal care. Furthermore, assistance from another person (usually a wife) was three times more frequent among sons than daughters. The care recipient's use of formal help was the same, however, regardless of the gender of the primary care-giver.

Phases and activities of the care-giving career

The sons' and daughters' care-giver career sequences are displayed in Table 2. Similar percentages of sons and daughters entered the three career phases. Every care-giver reported a care-giving task that fulfilled the criteria for the main support phase, but only about one-third experienced an escalation phase. A minority of the parents died at home, most of them suddenly and unexpectedly. This occurred for seven per cent of the daughter primary care-givers and six per cent of the sons. Four-fifths (81%) of the older people were admitted to a long-term care institution.

Activity and duration of the different phases

Table 3 reports the distribution and duration by gender of the care activities in the main support and escalation phases. For a larger percentage of sons than daughters, the principal activities in the *main support phase* were contacts and personal care. Nevertheless, practical help was by far the most common activity for both sons and daughters. The average duration was longer for daughters than for sons. In the *escalation phase*, personal care was a much more common activity for daughters than for sons. The average duration of the care provided by daughters was three times that as for sons.

In the majority of cases, the transition to the escalation phase was caused by a new major illness, such as stroke, pneumonia, hip fracture or

TABLE 3. Main support and escalation phase activities for son and daughter primary care-givers

Phase and activity	Sons	Daughters	p ¹
Main support phase			
<i>Primary care-giving activity</i>			
Contact	27%	18%	< 0.05
Practical help	58%	76%	
Personal care	16%	6%	
<i>Years of primary care-giving activity</i>			
Average	4.4	6.6	n.s.
Median	3.5	4.8	
Range	0.1–13	0.1–33	
Standard deviation	3.9	7.3	
Sample size	78	149	
Escalation phase			
<i>Primary care-giving activity</i>			
Contact	0%	0%	< 0.01
Practical help	52%	24%	
Personal care	48%	76%	
<i>Weeks of primary care-giving activity</i>			
Average	9	27	n.s.
Median	2.4	7.8	
Range	0.1–36	0.1–364	
Standard deviation	10.7	27.1	
Sample size	78	149	

Notes: 1. Chi-squared test of independence for the categorical variable; ANOVA test for the continuous variable.

another injury. In other cases there was a deterioration of a chronic illness, such as dementia, Parkinson's disease or a cancer. In the first category, some patients were treated at home, and others at hospital after which they were discharged to their home and further informal care. In the second category, the primary care-giver had to cope with escalating care needs. In both categories, the care-giver, the care recipient or both asked for permanent institutional care on average four months (17 weeks) after the start of the escalation phase.

Figure 1 presents the cumulative durations of the informal home care provided by the sons and daughters. The survival curves display the probability among all care-givers of various durations of care. For example, one-half (0.5) of sons were primary carers for at least two years, whereas for one-half of the daughters the duration was at least 3.8 years. For approximately 0.3 of both sons and daughters, the duration of care was at least 7.5 years. The cumulative duration curves for sons and daughters are similar until around 10 years, but then they diverge because a few daughters were involved in very long care durations. Among sons,

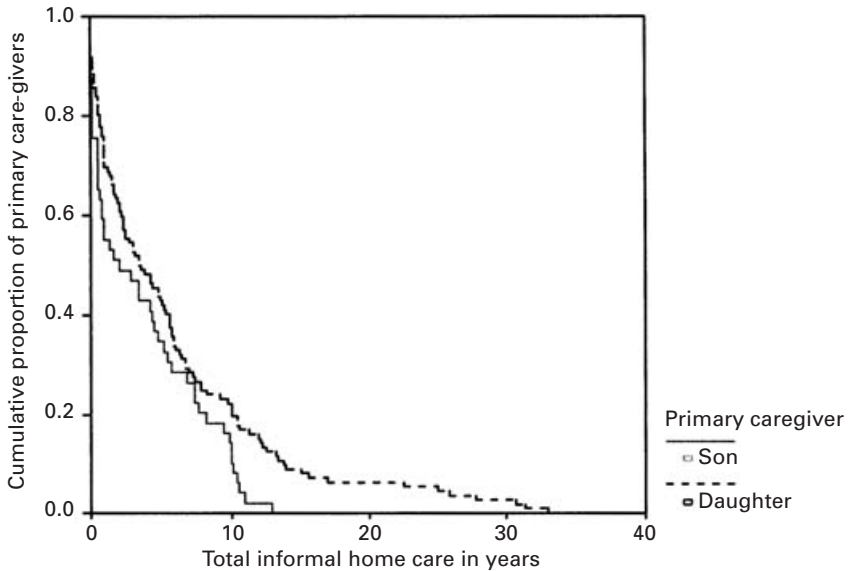


Figure 1. Cumulative durations of completed care episodes.

the longest care-giving episode was 13 years, but this duration was exceeded for 14 of the daughters, among whom the longest duration was 33 years.

The 14 daughters who provided care for an exceptionally long time did not differ from the other daughters on any of the personal attributes presented in Table 1. Nor did the content of their care-giving activities in the main support and escalation phases differ significantly. The duration of their main support phase averaged 21 years. Only three experienced an escalation phase, and its mean duration was two years.³ The 14 women reported different reasons for the very long courses of care-giving. Five said that they were motivated mainly by love, five saw it primarily as a duty, and four said that their old parents virtually forced them into a long care-giving career. Their own expressions are of interest: a 'loving' daughter said:

We had a very good relationship; we were not only mother and daughter, we were also friends. We could talk to each other about everything. It was very rewarding to be able to do so much for my mother. I enjoyed taking her out with me, because she was always so grateful and so positive. I have no negative experiences at all to report.

A 'forced' daughter said:

I was the only one who was allowed to dress her and wash her. Just me. I have quarrelled with her for many years, but one does a lot for one's family, as you

know. ... She was stubborn, difficult, grumpy and scheming. She thought that what I did was nothing. Many times I had to say to her: 'You really must behave better, or you will have to go into a nursing home'. I remember that things had to be done at once [and that] in the night my mother rang a cowbell. She let me try to get help in the home, but I was not to use the municipal services, but she did accept home nursing. I hardly ever left the house; I had to give up everything. I became lonely. It was almost like serving a prison sentence. My arms were cracking, and my back was worn out.

Turning to the *institutional phase*, the parents of 93 per cent of the daughters and of 94 per cent of the sons experienced an institutional phase. There was no gender difference in the type of institution to which the mother or father was admitted or in the duration of this phase (Table 2). The principal differentiator of the institutional phase was where the care recipient died (it should however be noted that 98 per cent of those who died in hospital were admitted directly from their home and not from a long-term care institution). The duration of the institutional phase did not differ significantly by gender. The average duration of hospitalisation was 17 days for the parents of son care-givers and 14 days for those of daughters. The average duration of residence in a long-term care institution was 3.9 years for the parents of both son and daughter carers.⁴ As to visiting frequency, 39 per cent of sons did so every day and 50 per cent at least weekly, while the comparable figures for daughters were 42 and 53 per cent respectively.

When an old person is admitted permanently to a long-term care institution, the care-giver's role is marked by both change and continuity. The most common activities that supplemented the care of the institution's staff were to take their parent out (41%), to provide practical help (21%), most frequently in the forms of banking, buying and repairing clothes, and helping to maintain the parent's room, and to give personal care (21%), mostly helping their mother or father with eating. Some of the care-givers described being troubled by guilt because they felt partly responsible for the separation. Twenty per cent of sons and six per cent of daughters reported feeling unhappy when the institution became the old person's permanent home, and 10 per cent of sons and 20 per cent of daughters said that their relationship with the disabled parent became more difficult. Thus, when a parent moves to a nursing home or residential care home, the burden on the care-giver is not automatically relieved (see also Lingsom 1997).

Discussion

This study has demonstrated that care-giving is dynamic and passes through different sequences of three phases that vary in duration. The

care-giving career typically comprises a long main support phase during which practical help is frequently given. Sometimes there follows a short escalation phase, when more hands-on care-giving is required prior to the institutionalisation and death of the relative. A complementary division of labour has been identified. The main contribution of the formal care system is to provide support to informal carers and personal care in institutions, whereas informal carers concentrate on the provision of extensive practical help, both at home and when their relative has been admitted to institutional care.

Care-giving careers in Larvik followed almost exactly the same sequence among sons and daughters, but the type of care-giving activities that they performed in each phase (contacts, practical help or personal care) differed slightly. The difference was most marked in the typically short escalation phase, when daughters performed more personal care. During the institutional phase, the type of institution and the frequency and content of care-giving tasks was largely the same for son and daughter primary care-givers. The durations of the care-giving activities in the first two phases were shorter for sons than for daughters, leading to a marked gender difference in the total duration of in-home care. The differential was however largely brought about by the minority of daughters who became involved in extremely long care-giving careers.

The similar sequence of phases in the care-giving careers of sons and daughters is most probably explained by the central role played by the care recipient's health in determining care needs. Another important factor in structuring the informal care-givers' careers was the supply of formal services, which was also the same for sons and daughters. The differences in sons' and daughters' care-giving activities and their durations have several possible explanations, namely gender differences in cultural norms, filial obligations, and in the practicalities of being able to provide care. Although the care-giving sons generally had more help than daughters from secondary care-givers, most of them (compared with fewer than half of the daughters) were employed full-time. This differential created unequal opportunities and capacities to provide care.

Variations in the duration of in-home care did not affect the parent's length of stay in an institution before death. This indicates that the daughters' longer care-giving careers were probably associated with their earlier acquisition of the role, rather than the sons' earlier withdrawal. This interesting pattern difference may be connected with differential role expectations, with a differential desire for contact (*n.b.* a larger proportion of daughters had lost a spouse), with fewer daughters being in paid employment, or with more daughters sharing their home with the parent. Although not documented here, the threshold at which a mother or father

is perceived to be in need of help may be lower for daughters than sons. It may also be that parents hold lower care-giving expectations from sons than daughters. The findings also indicate that sons may have responded to cultural taboos. Among those who provided hands-on personal care, 53 per cent of the sons did so for their mother and 47 per cent for their father. The corresponding figures for daughters were 82 and 18 per cent. It is not apparent that every mother would wish to receive intimate personal care from her son.

The results presented here differ in many respects from those of earlier studies. There are of course cultural and political differences between Norway and the United States (where most previous studies have been conducted), although how these are manifested in the specific circumstances of sons and daughters caring for their frail parents is not clear. Norwegian welfare and gender policies have aimed at equality for decades. This goal is now common to all major political parties and is a consensual value in contemporary Norway (Romoren 1996). It may be hypothesised that the similarity of men's and women's care-giving work is associated with the national culture and its policies. The Scandinavian welfare model promotes a shared responsibility for care-giving between family and society (Lingsom 1997). Over time this has meant that women are able to shape their care-giving roles.

In Larvik, frail older parents utilised formal home care services in a similar way regardless of the gender of their primary care-giver. Moreover, the similar durations of the institutional phase provides further evidence of a substantial erosion of gender differences in informal care practice. Nonetheless, during the last quarter of the twentieth century, differential gender-role expectations continued to have a marked effect upon who *became* the primary care-giver. The care-giving sons in this study were a small and selected group. Their care-giving activities do however demonstrate the potential for male care-giving that societal change may release.

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NOTES

- 1 The ranges of the ages in 1981 were 79 to 95 years for women, and 79 to 100 years for men. Although all in the sample were born in 1901 or before, four subjects had not

attained 80 years of age at the time of interview. The ranges of the ages of death were 79 to 102 years for women, and 80 to 100 years for men.

- 2 The age range was from 34 to 77 years for daughters, and from 40 to 72 years for sons.
- 3 The range for the main support phase was from 10 to 33 years, and the range for the escalation phase was from 0.1 to 7 years.
- 4 The ranges for the three durations were respectively 1 to 38 days, 1 to 70 days, and 0.01 to 16.4 years.

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Address for correspondence:

Tor Inge Romoren, Norwegian Social Research – NOVA, Pb 3223
Elisenberg, 0208 Oslo, Norway

e-mail: toringe@romoren.no