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Formal support, mental disorders and personal characteristics: a 25-year follow-up study of a total cohort of older people

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Abstract

The present study was designed to describe the pattern of long-term formal support received by people with mental disorders, and to investigate the relationship between the medical, psychological and social characteristics of the participants and types of formal support. This study is based on a cohort ($n = 192$) of people born in 1902 and 1903 in a community in Southern Sweden. The research participants were assessed using interviews, psychological tests and medical examinations. Information was collected about the use of primary healthcare and social services. The first assessment took place when the cohort was aged 67 years, and then on eight further occasions until they were 92. The participation rate ranged from 72% to 100%. During the observation period of 25 years, 53% of people with dementia eventually received both home help and institutional care compared to 34% of people with other psychiatric diagnoses and 12% of people with good mental health. The last group had all physical health problems and/or problems with activities of daily living. However, 35% of the dementia group, 46% with other psychiatric diagnoses and 52% of people with good mental health did not receive any formal support. Males and self-employed people were significantly less likely to use formal support. The institutionalised group reported loneliness significantly more often than the other two groups. In a logistic regression analysis, loneliness, low social class, high blood pressure and low problem-solving ability were predictors of formal support use. People with a mental disorder, including dementia, were significantly more likely to use formal support compared to people with good mental health. Social factors were the main factors predicting formal support.

Keywords: formal support, longitudinal, mental disorders, multidisciplinary

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Introduction

In the 1980s, the importance of providing social and medical care (including diagnostic facilities) for elderly people with dementia was recognised (Annerstedt 1995). In addition, special attention has been given to the situation of family members caring for relatives with severe, long-term dementia. Research on geriatric mental disorders over the past 10–15 years has focused on dementia, and comparatively few studies have

analysed the entire spectrum of psychiatric disorders experienced by old people.

The present authors studied the full range of mental disorders and formal support using a longitudinal prospective study in a cohort of elderly people. For the purposes of this paper, formal support is defined as the use of home help services, old age home and/or nursing home services. The authors are not aware of any other longitudinal study of elderly people that investigates over a 25-year follow-up period the whole range of

mental disorders and their relationship to formal support patterns. Findings from the present study have been reported earlier (Samuelsson & Sundström 1988, Hagberg *et al.* 1991, Samuelsson *et al.* 1993, Samuelsson *et al.* 1994, 1998). However, none of these earlier research reports included analyses of different mental disorders and formal support extending over the entire 25-year period.

Calsyn & Winter (2000) reviewed the research about predictors of service use by elderly people, and found that living alone and state of physical health consistently predicted the use of home help service. The review was much less conclusive about the importance of social variables. This finding might be because of differences between the studies which were reviewed in terms of the length of the follow-up periods; for example, longer follow-up periods tend to provide more diverse information about diseases and changes in support. Living alone consistently predicted use of community services when other network supports were taken into account.

Mental disorders seems to be another determinant of service use. In a population study of people suffering from dementia in Stockholm, Fratiglioni *et al.* (2001) reported that 47% of the study participants (age ≥ 77 years) were institutionalised at the beginning of their study and 93% 7 years later. Smith *et al.* (1999) found that functional status and mental morbidity were major contributors to nursing home placement.

A Norwegian population study of people aged ≥ 80 years followed from 1981 until they were all dead in the year 2000 (Romøren 2001) reported that 48% eventually used home help services and that 73% ended their lives in institutional settings. These rates are much higher than coverage rates for home help and institutional care during this time period in Norway.

In a previous paper based on the same research project as the one presented here, information about symptoms, diagnoses and contacts with the primary healthcare system from the ages of 67 to 84 years was reported (Sundström *et al.* 1991). Participants with mental disorders tended to establish contact earlier than mentally healthy persons, and to maintain contact with their general practitioner over a longer time period. Dementia patients had also more contact with the primary healthcare system than non-demented people. Sjöbeck (1994) confirmed this finding in her study.

The aims of the present study were to:

- 1 describe formal support (home help and institutional care) patterns in relation to people with mental disorders between the ages of 67 and 92 years, including those who died before the age of 92; and

- 2 investigate the relationships between the medical, psychological and social characteristics of participants when they were 67 years and use of formal support during a 25-year follow-up period.

Subjects and methods

Research participants

The cohort ($n = 192$) comprised every 67-year-old person living in the Dalby Primary Health Care District during the year 1969–1970. Dalby is situated 40 km from Malmö, the third largest city in Sweden. Follow-up began in 1970 with repeated examinations and interviews, usually every other year up to 1985. Further assessment or examination was undertaken in 1994–1995, when the survivors had reached 92 years of age. The rate of participation at 67 years of age varied from 76% to 81% in the medical, psychological and social examinations. In the eight following waves, only one person dropped out. At 92 years of age, all the survivors participated. Eighty-nine per cent of the study group died between the ages of 67 and 92 years.

Thirty-eight people refused to participate in the examination at 67 years of age or died (six men) prior to the examinations. Information was collected on mental diagnoses and formal care for the non-participants, as well as for the 12 people who moved out of the health-care district during the 25-year period. The non-participants had lived previously in urban rather than in rural areas. There were no differences between participants and non-participants in terms of gender, marital status, mobility during earlier life and social class. Non-participant men had higher income levels than participating men, whilst the opposite was true for women (Samuelsson *et al.* 1994). Among non-participants, 11% had dementia, 11% had symptoms of other mental disorders and 79% were mentally healthy according to health records.

The general level of education was approximately the same in the cohort as in the corresponding age group for the whole country. Most of the men had worked in manual occupations (86%), and most women (88%) in household work or manual work. This is a fairly typical pattern for a rural, turn-of-the-century cohort in Sweden. Two per cent lived in old people's homes at 67 years of age. The rest lived in the community, and 15% lived alone. Males were clearly over-represented in the first examination (59% were men and 41% women), a pattern which was typical for older rural populations in that period (Quensel 1945).

Methods

The medical information and psychological data were collected at the local healthcare centre by a physician and a team of psychologists. These examinations took approximately 1.5 days to complete. The medical data, collected by a physician, included: a full history of current and earlier diseases; blood tests, urine analysis, electrocardiograms and laboratory tests; as well as the results of a standard physical examination. Psychological tests measured personality, cognition, needs, attitudes, adjustment and intelligence. In addition, a social worker interviewed the subjects at home about their earlier and present life situation. This took approximately 2 hours (Samuelsson 1981). Furthermore, all contacts with medical and social services over the years of the study were recorded and information was extracted from death certificates.

Predictors of support

Social measures

A questionnaire with items based on previous Scandinavian studies (Stehouwer & Ostergard 1967, Johansson 1970) of elderly people was used to assess social factors. The following variables are included in the present analysis: social class, economic status, urban/rural living (during the life span), educational level, marital status, having children, social support and loneliness.

Social class was coded according to the Swedish Socioeconomic classification (SEI) coding system: self-employed (including farmers and business owners), white-collar and blue-collar workers (Statistics Sweden 1982). Economic status was obtained from taxable income from 65 to 68 years of age. Educational level was measured in number of school years. Information about years living in an urban/rural area from birth to 67 years of age was collected from parish records. Loneliness was assessed on a four-point Likert scale and then dichotomised: (1) never/seldom; or (2) sometimes/often. Information about marital status and loneliness was collected at 67 years of age and before an individual moved into an institution.

Psychological measures

Cognition was assessed by psychometric tests which measured: logical inductive reasoning; verbal, numeric and spatial abilities; intelligence; and motor speed (Lindberg *et al.* 1980). A factor analysis produced indicators of four cognitive functions labelled: theory, motor, problem-solving and knowledge. These factors were used in the present analyses. Life adjustment was based on a clinical interview and coded from 1 to 3:

(3) 'good' adjustment to present life situation – satisfactory social integration, spends time on interesting activities; (2) 'fair' adjustment – most things work well, conflicts in some areas (e.g. social interaction, few activities, and some worries); and (1) 'poor' adjustment – conflicts in life (e.g. fear of the future, isolation, negative or aggressive behaviour). Attitude scales based on the semantic differential method (Osgood *et al.* 1967) were used to assess the degree to which participants viewed their future in positive or negative terms, and the extent to which they held a positive self-concept.

Medical variables

The presence or absence of the following disorders was assessed at 67 years of age: diabetes mellitus, rheumatoid arthritis, angina pectoris, lung disease, gastrointestinal disease, liver disease, kidney disease or cancer, and any of the symptoms dyspnoea, vertigo and headache (together called dizziness): (1) no diseases; and (2) one or more diseases. Use of sleeping pills, analgesics and sedative/hypnotic medication was also assessed.

Data on type of mental disorder was collected for each person, and date of death for those who died before 92 years of age. Four men and 13 women survived beyond the age 92 years. Diagnostic classification systems (National Board of Health and Social Welfare 1970) have changed during the follow-up period, but the changes were just changes of the codes attributed to each mental disorder. However, the underlying definitions of disorder were the same. Incidence of mental disorders was calculated for the entire 25-year period.

The main outcome variable was the use of formal support services, as indicated in records from home healthcare and social institutions. The type of formal support was coded as: (1) no formal support (2) only home help, and (3) home help and institutional care.

Statistical analysis

The Pearson chi-square test was used to identify any associations between social, psychological and medical variables, and the formal support category. The Kruskal–Wallis test was used to test for differences in ordinal or (possibly skewed) interval variables between the three support categories. A logistic regression analysis included all 23 variables to identify whether or not any were significant predictors of the use of different types of formal support services. A goodness-of-fit measure was obtained by the Hosmer and Lemeshow test that gave a non-significant *P*-value of 0.31.

Table 1 Mental disorders and formal support during a 25-year period (numbers and row percentage)

Diagnosis	No formal support		Home help		Home help and institution		Total	
	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage
Dementia	6	35	–	–	11	65	17	100
Other mental disorder	15	44	7	21	12	35	34	100
Both dementia and other mental disorder	3	38	1	12	4	50	8	100
Mentally healthy	50	53	23	24	22	23	95	100
Total	74	48	31	20	49	32	154	100

Results

Formal support and mental disorders between 67 and 92 years of age

Significantly more people with mental disorders, including dementia, received formal support (institutional care and home help) compared with mentally healthy persons. The proportion of people who received home help and were later relocated to institutions increased with age and the increase was especially evident for people with dual diagnoses. The mean age of mentally healthy persons who were relocated to institutions was 82.6 years, and this was 76.8 years for people with both dementia and other mental disorders, 80.2 for other mental disorders and 81.2 years for persons with dementia. However, 35% of people with dementia and 44% of people with other mental disorders did not receive any formal support during the 25-year period compared to 53% of the mentally healthy subjects (Table 1).

One person with dementia who also had other mental problems received only home help. The corresponding figure for people with other mental diagnoses was 21%, and among mentally healthy persons, 23%. A combination of home help and institutional care was used much more frequently by people with dementia or with other mental disorders (mainly depression and intellectual disability) than by the mentally healthy group. A direct move from home to an institutional setting without previous use of home help was common only among people with dementia (35%) or other mental disorders (17%). Some people with mental disorders refused to accept home help.

Medical, psychological and social characteristics, and their relationship with formal support

In the bivariate analysis, some social variables appeared to be significantly related to receipt of formal support. Females received home help and institutional care much more often than men; 58% of the men did not

receive formal support compared to 33% of women. White- and blue-collar workers received formal support significantly more often than the self-employed. Two out of three people with dementia were married at 67 years of age. Most of the people who did not receive any formal support (35%) stayed at home and received informal support.

The institutionalised group experienced loneliness at the age of 67 years more often than any other support group (see Table 2). Thirty-two per cent felt lonely 'sometimes or often' before moving to an institution. None of the other social variables was significantly related to formal support.

None of the psychological variables which were assessed at age 67 (using four factors of cognitive tests, future view, self-concept and life adjustment) predicted later patterns of support or service use (*P*-values varied between 0.47 and 0.70).

None of the eight medical variables which were assessed at 67 years of age were significantly associated with receipt of services at follow-up (*P*-values = 0.06–0.38). Compared to other groups, more people who were relocated to institutions were diagnosed as having hypertension at the age of 67 years (*P* = 0.06). An update of the information in medical journals just before the time of relocation to an institution showed that all mentally healthy persons had problems with activities of daily living (ADLs) and physical diagnoses, sometimes in combination with social problems.

The regression analysis tested the extent to which 23 medical, psychological and social variables predicted formal support. Included in the final model were social class, blood pressure, the cognitive factor 'knowledge function' and loneliness. White- and blue-collar workers were three times more likely to be recipients of formal care. Loneliness increased the risk for receipt of formal support by two and a half times; low knowledge function had an odds ratio value of 1.20, indicating increased risk for receipt of formal support; and normal blood pressure decreased the risk of using formal services (odds ratio value = 0.36) (Table 3).

Table 2 Associations between social variables and formal support groups (row percentage, mean and median values)

Social variable	Number	Home help and institution	Home help only	No formal support	<i>P</i> -value
Social class (%)*					
self-employed	55	14.5	16.4	69.1	0.002
white collar/non-manual	14	42.9	21.4	35.7	
blue collar/manual	85	41.2	22.4	36.5	
Gender (%)*					
male	91	20.9	20.9	58.2	0.001
female	63	47.6	19.0	33.3	
Assessed income (mean)†		2.2	2.4	2.4	0.32
1 (low)	33	51.5	15.2	33.3	0.04
2	54	20.4	27.8	51.9	
3	43	25.6	14.0	60.5	
4 (high)	20	35.0	25.0	40.0	
Education level (median)†	151	7	7	7	0.32
Rural/urban living (%)*					
rural	108	31.5	20.4	48.1	0.52
mixed rural/urban	35	34.4	14.3	51.4	
urban	10	20.0	40.0	40.0	
Marital status (%)*					
single	31	45.2	16.1	38.7	0.10
married	105	26.7	19.0	54.3	
widowed/divorced	18	38.9	33.3	27.8	
Children (%)*					
no children	38	34.2	15.8	50.0	0.72
has children	113	31.3	21.7	47.0	
Loneliness (%)*					
never/seldom	117	26.1	20.2	53.8	0.03
sometimes/often	29	50.0	20.0	30.0	

* Statistical test: Pearson chi-square.

† Statistical test: Kruskal–Wallis.

Table 3 Result of logistic regression predicting different forms of formal support services: (95% CI) 95% confidence interval

Variable	Odds ratio	95% CI	<i>P</i> -value
Social class			
self-employed	1.00	–	–
white collar	3.03	0.82–11.19	0.10
blue collar	2.97	1.33–6.62	0.01
Blood pressure	0.36	0.15–0.86	0.21
Knowledge level	1.20	0.99–1.45	0.06
Loneliness	2.51	0.95–6.65	0.07

* The number of cases included in the analysis was 139.

Discussion

The present study confirmed that men and women with a mental disorder, including dementia, received formal support more often than people without a mental disorder. Use of home help and institutional care increased with age and the increase was especially strong for people

with mental disorders. However, as many as 35% of people with dementia and 46% of people with other mental disorders did not receive any formal support during the 25-year period or before death, compared to 52% of mentally healthy people. Males, the self-employed and people with a high income received significantly less formal support. The institutionalised group experienced loneliness significantly more often than other groups. Logistic regression analyses indicated that loneliness, social class, high blood pressure and low problem-solving function were risk factors for receiving support.

It is also worth noting that 45% of people who were admitted to an institution suffered from dementia or other mental disorders, compared to 23% of mentally healthy people. Institutional care was used as a last resort after exhausting the resources of families and/or home help when the person lived alone.

It is official policy in Sweden to support elderly people in the community, particularly through home help

services (Thorslund 1988). Dementia patients make up a small but growing fraction of home help clients, and they use a disproportionate amount of the total budget. Nevertheless, the present study indicates that the policy does not seem to have worked well for a considerable number of people with mental disorders. This fact may explain the pattern of relocation into institutions observed in this study. Alternatively, it may be a result of the home help service being unable to care for people with dementia and mental illness in an appropriate manner (Sundström & Cronholm 1991, Socialstyrelsen 2000).

A bivariate analysis of predictors of formal support during the follow-up period indicated that females received significantly more formal support. To some degree, this might depend on their longer survival. Older women are more likely to be widowed, in need of formal care and living alone without the support of a husband. These findings are supported by a review by Steverink (2001), which indicated that important predictors of formal support are gender, age, living alone and the unavailability of informal care. The year of widowhood and year of relocation to an institution appeared to be associated, thereby suggesting that there are particular vulnerable time points when formal support may be required.

The self-employed received significantly less formal support than white- and blue-collar groups. The same pattern was found in an earlier study up to the age of 80 years in the Dalby cohort (Samuelsson & Sundström 1988) as well as in National studies [Statistic Sweden (SCB) 1993]. This might be explained by greater use of private help or a more conservative view concerning public support among the self-employed. It may also be a result of better health among the self-employed, although the nine medical variables did not show any significant differences between the classes.

A higher proportion of people in the institutionalised group expressed feelings of loneliness when they were first interviewed at 67 years of age. However, using the latest information collected before relocation on loneliness indicated that loneliness was not the main reason for admission to an institution (only 32% of people admitted to an institution sometimes or often felt lonely).

The nine medical variables at the age of 67 years did not predict later support patterns. The present results might be explained mainly by the fact that especially the physical status is reversible, and at the time for relocation to institution, the current health problems may have been a more important reason to relocate. Problems with ADLs are a prerequisite for relocation to institutions in Sweden. The information in the person's medical journal just before the time of relocation to institution showed that all of the mentally healthy per-

sons had problems with ADLs and physical diagnoses, sometimes in combination with social problems. These problems appear to have been the main reason for the relocation of the mentally healthy subjects. As already shown, mental health problems during the 25-year period were important for relocation.

Cognitive predictors of dementia and formal support are significant. First, low episodic memory capacity (Skoog 1994) or mild cognitive impairment (Petersen *et al.* 1997) have been related to the incidence of dementia. Secondly, a generally low level of cognitive functioning by way of less compensatory mechanisms would increase the risk of developing dementia (Fratiglioni *et al.* 1991) and give rise to more behaviour problems during the progression of the disease (Baltes & Baltes 1990). The 'early sign hypothesis' was difficult to verify because of the present authors' insensitive measures of episodic memory at 67 years of age. There was some support for the 'low cognitive level hypothesis'. Some individuals with a low level of 'general knowledge' were more likely to use home help and become institutionalised when demented or affected by other mental disorders. The results indicate that care and services for the elderly with mental disorders should be highly individualised, and include strategies which support coping for individuals with behaviour problems (Hagberg 1997).

In this local cohort, mental disorders other than dementia were twice as prevalent as dementia. Most mental disorders are difficult to identify in their early stages, even though the primary healthcare staff responded quickly and reported any general complaints or symptoms. Knowledge of the overall medical and social situation of the patient, continuity of professional contacts, and appropriate staff training are required in order to interpret these potential signs and symptoms. Better diagnostic precision, care and support are likely when there is effective coordination between healthcare and social services.

A strength of the present study is that the cohort included everyone living in a health district at a certain time-point. Information on formal support on non-participants and the deceased is also available. Only one person dropped out during the follow-up periods. Extensive multidisciplinary examinations have been completed, and information from medical and social records collected. The present authors have not found any other study with the same length of follow-up period and a prospective cohort design.

A weakness is that the present results are based on a relatively small local population, which gives relatively low statistical power and uncertain generalisability. Furthermore, many of the postulated predictor/variables may have changed during the 25-year period, such

as cognition, health status and social network. Information about the predictive variables used in the analyses was mainly collected when the cohort was 67 years of age. When interpreting the present results, one must bear in mind that changes in these variables during the period of study might influence the relationships with formal support. However, updated information on level of ADLs, physical health, marital status and loneliness was included in the analyses as well as non-reversible variables as social class, education level and urban/rural living. The Dalby study is also based on one cohort, and thus, cannot provide information on cohort and period effects.

Finally, socio-political and cultural differences must not be overlooked when analysing support patterns and health. The study group were ageing during the 1970s and 1980s when the Swedish welfare society was at its most generous, but the 1990s was a period of cut-backs of institutional care and home help services. Therefore, support patterns and related variables may differ for more recent cohorts in Sweden. It is presently harder to obtain formal care today than previously (Sundström *et al.* 2002).

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