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Informal Caregivers of People with Dementia: Problems, Needs and Support in the Initial Stage and in Subsequent Stages of Dementia: A Questionnaire Survey

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Abstract: *Objective*: The ageing of the population is expected to lead to an increase in the prevalence of dementia. Providing support to informal caregivers is essential to promote their wellbeing and prevent serious caregiver burden. The aim of the study is to investigate whether differences occur between the initial and later stages of dementia in terms of (1) problems experienced by informal caregivers in the provision of care, (2) use of professional support by persons with dementia, (3) informal caregivers' needs for additional professional support.

Methods: The data were collected within the framework of the Dutch National Dementia Program, which was instigated in 2005 by the Dutch Ministry of Health, Welfare and Sport to improve integrated care for people with dementia and their informal caregivers. This paper is based on data of a questionnaire survey among 1494 informal caregivers, collected between September 2007 and December 2008.

Results: Most informal caregivers (98-99%) experienced problems in caring for a person with dementia, irrespective of the stage of the illness process. In later stages, informal caregivers more often experienced problems in their social networks. Most dementia patients (87-94%) received ambulatory professional support.

Conclusions: Since informal caregivers indicate a need for additional professional support in all stages of dementia, professional support should be provided during the *entire* illness process. Informal caregivers need advice on how to cope with symptoms of dementia, how to deal with behavior problems and receive more information about (early and advanced stages of) dementia and the supply of support.

Keywords: Dementia, informal caregivers, illness stages, professional support, transition, survey.

INTRODUCTION

Dementia is characterized by a progressive loss of social and cognitive functions. During the course of the illness, people with dementia become increasingly dependent on the care of others. Both the number and severity of symptoms increase and daily functioning and participation in social activities become increasingly difficult. This sometimes leads to a situation in which care is needed over a 24 hour period [1]. Care may be needed for a prolonged period of time, because the illness process usually extends over several years (seven years on average; [2]).

The ageing of the population is expected to lead to an increase in the prevalence of dementia [3, 4]. The amount of available professional care is, however, not expected to rise in line with the growing demand in the ageing population. As a consequence, people with dementia will become increasingly dependent on the care of informal caregivers, such as their spouses, their children, other relatives or friends. Informal care is not only provided when the patient is living at home [5], but also when the person with dementia is admitted to a long-term care facility [6].

The provision of informal care can be a serious burden for caregivers and can negatively affect their mental and physical health, particularly if care is provided frequently or for a prolonged period of time [7]. The duration of caregiving before admission in a nursing home was the strongest predictor for the decreased perceived burden after admission [8]. The most salient variables affecting the occurrence and timing of institutional placement for persons with dementia were the caregivers' depression scores and the care recipients' behavioral change scores over time [9]. The longer period of time spent in caregiving could represent increasing demands of care and thus increased sense of burden.

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This caregiver burden is not only associated with the provision of care, but also with the fact that informal caregivers have to learn to cope with the illness and changes in the behavior of the person with dementia. The progressive and often unpredictable course of dementia poses considerable challenges to informal caregivers. Carers reported losses at different levels within the family, and a range of methods used to cope with loss and to maintain their family functioning were identified [10]. The majority of caregivers receives little informal support, has poor knowledge of available formal services, and has difficulty planning ahead for the relative's future care needs. Caregivers themselves report a lack of preparedness to provide care [11]. So, providing support to informal caregivers is therefore essential to promote their wellbeing and prevent serious caregiver burden.

In the Netherlands and other Western European countries, various professional support services, such as 'Alzheimer meeting points for patients and relatives', are available [12]. In spite of this, informal caregivers' needs for support often remain unmet, because they have difficulties finding the appropriate services and because professional care appears insufficiently attuned to informal caregivers' needs [13,14].

To be able to adequately support informal caregivers, insight into the problems they experience in caring for a person with dementia and in their needs for support, is crucial. Although some studies have addressed the needs of informal caregivers [13-15], few have investigated whether informal caregivers' problems and needs change during the course of the illness. The increase in illness symptoms may cause caregivers of persons in later stages of dementia to experience more problems and to have a stronger need for additional professional support than caregivers of persons with initial symptoms of dementia [16]. On the other hand, it has been suggested that informal caregivers develop coping strategies and receive an increasing amount of professional support during the illness process, which may improve their ability to handle the changing condition and increasing needs of the person with dementia [17]. The question arises, therefore, whether there are differences between informal caregivers' needs and problems in various stages of the illness process. Answering this question is important to improve the tailoring of nursing care and other supportive services to informal caregivers' needs. This paper therefore investigates whether differences occur between the initial stage and later stages of dementia in terms of (1) the problems experienced by informal caregivers in the provision of informal care, (2) the use of professional support by persons with dementia, and (3) informal caregivers' needs for additional professional support.

METHODS

The data presented in this paper were collected within the framework of the Dutch National Dementia Program, which was instigated in 2005 by the Dutch Ministry of Health, Welfare and Sport to improve integrated care for people with dementia and their informal caregivers. The program included a survey to investigate the problems and needs experienced by informal caregivers of people with dementia [18].

The recruitment of informal caregivers was conducted by trained volunteers from the Dutch Alzheimer's Association (a national association which aims to improve the situation of persons with dementia and their caregivers) and took place during support and information meetings organized by this Association. The volunteers provided informal caregivers with structured verbal and written information about the study and asked them to fill in the survey questionnaire, following a procedure described in the questionnaire manual [19]. In addition, some informal caregivers were recruited through professional care providers (e.g. case managers and professionals in day care or nursing homes). Since the volunteers did not systematically register how many informal caregivers were asked to participate in the study, we cannot calculate a reliable response rate.

This paper is based on data of 1494 informal caregivers, collected between September 2007 and December 2008.

Questionnaire

The questionnaire addresses problems and needs that informal caregivers may experience during the various stages of dementia [15]. The first three questions relate to problems that could have occurred during the initial occurrence of the symptoms of dementia (e.g. not being sufficiently familiar with available support options when the person was diagnosed with dementia, and not having received sufficient information about the symptoms and progression of dementia). Informal caregivers were asked whether they had experienced these problems. The subsequent questions refer to problems that may have occurred during the course of the illness, such as dealing with behavioral changes in the person with dementia, problems in the communication with health care providers, and the loss of contact with family and friends. Informal caregivers were asked to indicate whether these problems had occurred in the past two months.

The questionnaire also investigates which types of ambulatory professional support the person with dementia is currently receiving and the informal caregiver's needs for additional professional support in caring for the person with dementia.

Additionally, informal caregivers were asked to indicate since when the person with dementia had shown symptoms of dementia. More details of the contents and characteristics of the questionnaire are described elsewhere [15,19].

Analyses

We used informal caregivers' evaluations of the period of time since the first occurrence of the symptoms of dementia to distinguish between people in the initial and subsequent stages of dementia. The initial stage was operationalized as having had symptoms of dementia for less than a year. In addition, a distinction was made between two stages in the subsequent course of dementia: having symptoms of dementia for 1 to 4 years, and for 4 years or more.

The characteristics of people with dementia and their caregivers were analyzed with descriptive statistics. Chi-square tests, with $p < 0.01$, and using SPSS 14.0, were used to test differences between informal caregivers of persons in the initial stage and in later stages of dementia.

Ethics

Informal caregivers received information about the aim and content of the research in an information letter which was sent together with the questionnaire. The anonymity of the informal caregivers was strictly preserved throughout the data entry and analysis process. According to Dutch law no approval of a Medical Ethics Committee is needed for survey research, not involving any intervention.

RESULTS

Characteristics of the participating informal caregivers and the persons with dementia are reported in Table **1**. Eighty-nine informal caregivers (6.0% of the total sample) had a relative in the initial stage of dementia (i.e. having had symptoms of dementia for less than a year), 744 (49.8%) informal caregivers had a relative who had had symptoms of dementia for 1-4 years, and 661 (44.2%) had a relative who had had dementia symptoms for 4 years or more.

Informal caregivers in the three stages of dementia did not differ significantly with respect to age, gender and the frequency of providing informal care. During the later stages of dementia (≥ 1 year), informal care was mainly provided by the spouse and children of the person with dementia, whereas the amount of care provided by others (e.g.

Table 1. Characteristics of Participating Informal Caregivers and Persons with Dementia (in Percentages)

Informal Caregivers	**Stages of Dementia**[a]			**Total N=1494**	**p**
	< 1 Year N=89	**1-4 Years N=744**	**≥ 4 Years N=661**		
Age					0.03
< 45 years old	1.1	6.2	3.7	4.8	
45 - 65 years old	50.0	42.9	39.1	41.6	
65 - 85 years old	46.6	47.4	54.5	50.5	
≥ 85 years old	2.3	3.6	2.6	3.1	
Gender					0.43
female	77.5	70.9	71.8	71.7	
male	22.5	29.1	28.2	28.3	
Relationship to the Person with Dementia					0.00*
spouse	54.5	53.1	64.4	58.2	
son/daughter (in-law)	29.5	41.5	31.6	36.4	
other	15.9	5.4	4.0	5.4	
Frequency of Providing Informal Care					0.64
daily	58.4	58.5	63.3	60.6	
3-6 times a week	19.1	19.0	16.3	17.8	
1-2 times a week	16.9	18.4	16.8	17.6	
< 1 time a week	5.6	4.1	3.6	4.0	
Persons with Dementia					
Age					0.00*
< 45 years old	0.0	0.1	0.2	0.1	
45 - 65 years old	10.3	3.7	8.6	6.3	
65 - 85 years old	72.4	69.8	69.4	69.8	
≥ 85 years old	17.2	26.3	21.9	23.8	
Gender					0.43
female	55.1	55.0	51.6	53.5	
male	44.9	45.0	48.4	46.5	
Current Living Situation					0.00*
in his/her own home or with a child	85.4	79.6	65.3	73.6	
in nursing home or home for the elderly	14.6	20.4	34.7	26.4	

*Differences between the stages of dementia are statistically significant (chi-square test, $p < 0.01$)

[a] Evaluated by the informal caregiver.

neighbors or friends) decreased. Persons in the later stages of dementia were significantly older and more frequently lived in a nursing home or home for the elderly than persons in the initial stage of dementia.

Problems Experienced by Informal Caregivers

Almost all informal caregivers experienced problems in caring for the person with dementia. This applied to informal caregivers of people in the initial stage of dementia (98.9% experienced problems), as well as to informal caregivers of people who had had symptoms of dementia for a longer period of time (1-4 years: 99.1%; $\geq$ 4 years: 98.0%; chi-square test, $p>0.01$). The problems most frequently mentioned are listed in Table **2**. Changes in the behavior of the person with dementia and dreading the person's admission to a nursing home were the problems that informal caregivers most frequently mentioned in the initial stage as well as in subsequent stages of dementia.

Table **2** shows some significant differences in problems experienced by informal caregivers of people in the initial stage and in subsequent stages of dementia. Informal caregivers of people in subsequent stages of dementia more often experienced problems in their social networks than informal caregivers of people in the initial stage of dementia. This is reflected by the finding that 49.1% of the informal caregivers of persons who had had symptoms of dementia for at least 4 years reported having less contact with friends and acquaintances, in contrast with a mere 25.6% of informal caregivers of persons in the initial stage of dementia. Problems such as loneliness and less contact with relatives were also mentioned significantly more often by informal caregivers of persons in subsequent stages of dementia.

Informal caregivers of persons in later stages of dementia often experienced the care for their relative with dementia as physically too demanding. They also feared that health problems might occur because of the relative having difficulties in communicating physical ailments. They reported these problems significantly more often than informal caregivers of people in the initial stage of dementia (chi-square test, $p<0.01$).

The Use of Ambulatory Types of Professional Support

Most informal caregivers reported that their relative received some kind of ambulatory professional support, in the initial stage of dementia (86.5%), as well as in later stages (1-4 years: 91.1%; $\geq$ 4 years: 93.6%; chi-square test, $p>0.01$). Table **3** presents the various types of professional support used. Day

Table 2. Problems Experienced by Informal Caregivers in Caring for a Person with Dementia (in Percentages)

Problems	Stages of Dementia[a]				
	< 1 Year N=89	1-4 Years N=744	$\geq$ 4 Years N=661	Total N=1494	p
Has problems dealing with changes in the behavior of the person with dementia	75.9	79.1	78.0	78.4	0.73
Dreads the person's admission to a nursing home	59.0	62.0	58.7	60.4	0.45
The care for the person with dementia is often emotionally too demanding	48.2	52.8	58.2	54.9	0.06
Was not sufficiently familiar with available support options when the person was diagnosed with dementia	46.6	47.0	51.0	48.7	0.30
Is worried that the behavior of the person with dementia will cause unsafe situations in or around the house	42.0	49.7	42.1	45.9	0.02
Has less contacts with friends or acquaintances due to the illness of the person with dementia	25.6	36.7	49.1	41.5	0.00*
Cannot leave the care for the person with dementia to others when needed	39.5	42.4	39.1	40.8	0.47
Feels lonely	23.3	36.9	47.0	40.6	0.00*
Cannot adequately cope with the grief over the deteriorating situation of the person with dementia	39.8	39.5	41.2	40.3	0.81
Finds it hard to make decisions for the person with dementia	45.3	39.3	39.4	39.7	0.55
Thinks that health problems may occur because of the person's difficulty with communicating physical ailments	27.3	34.2	45.1	38.6	0.00*
Has received insufficient information about the symptoms and progression of dementia	34.5	33.9	41.8	37.4	0.01
Has the feeling of being on his/her own in caring for the person with dementia	31.8	36.1	38.6	36.9	0.38
Does not sufficiently know how to deal with the person's resistance	39.3	37.7	32.0	35.3	0.07
The care for the person with dementia is often physically too demanding	14.9	27.7	37.0	31.0	0.00*
Contacts with relatives have been diminished due to the illness of the person with dementia	16.1	24.3	36.3	29.0	0.00*

The questionnaire addressed a total number of 35 problems. This table reports the problems most frequently mentioned by informal caregivers.

*Differences between the stages of dementia are statistically significant (chi-square test, $p < 0.01$)

[a] Evaluated by the informal caregiver.

treatment, day care and assistance with housekeeping were used most often. We expected that because of the progress of the disease, and because people might be better informed about support options when time progresses, the use of professional support would increase over time. However, contrary to our expectations, the number of persons with dementia who made use of specific types of professional support did not significantly increase (see Table **3**). The majority (61.7%) of the persons, who received some kind of professional support, used more than one type of support concurrently. Also this percentage did not differ significantly for persons in the three stages of dementia (chi-square test, p>0.01). On average, persons with dementia concurrently received 1.8 types of ambulatory professional support (sd. 1.3).

Needs for Additional Professional Support

Most informal caregivers indicated a need for additional professional support in caring for the person with dementia. This percentage was comparable for caregivers of persons in the initial stage (< 1 year; 65.2%) and in later stages of dementia (1-4 years: 60.9%; ≥ 4 years: 58.4%; chi-square test, p>0.01). The majority (88.9%) of the informal caregivers, who indicated a need for additional professional support, wanted support on more than one domain. The main domains on which informal caregivers needed additional support are listed in Table **4**. This table shows that the needs for additional support vary, but mainly concern advice and information. Informal caregivers of persons in the initial stage and in subsequent stages of dementia reported needs for additional professional support on similar domains, although a significant difference between these groups is the need for information about the availability of professional support in the region. Significantly more informal caregivers of persons in the initial stage of dementia (27.0%) than in later stages of dementia (1-4 years: 19.4%; ≥ 4 years: 14.5%; chi-square test, p<0.01) indicated a need for this kind of information.

DISCUSSION

The future increase in the number of people with dementia [3,4] is not expected to be reflected by an increase in the availability of professional care. Informal caregivers will therefore become increasingly important in the care for people with dementia. Insight into informal caregivers' problems and needs is essential to develop a care supply that is tailored to these needs, and that will positively affect informal caregivers' burden and wellbeing. To our knowledge, this study is the first to investigate the differential problems and needs of informal caregivers in various stages of dementia.

The majority of informal caregivers experienced problems in caring for a person with dementia, regardless of the stage of the illness process (cf. 19). In the initial stage as well as in later stages of dementia, informal caregivers mainly experienced problems in adapting to changes in the behavior of the person with dementia. Previous research has shown that these behavioral changes negatively affect informal caregivers' wellbeing [20-22]. Informal caregivers also dreaded the person's admission to a nursing home during all stages of the illness process.

Although dementia is characterized by an increase in the number and severity of symptoms and in the extent to which the person is dependent on the care of others, these changes were not reflected by an increase in the use of various types of ambulatory professional support in our sample. Our data did, however, not concern the frequency with which these types of support were provided, and an increase could have occurred in that respect.

A considerable percentage of informal caregivers indicated a need for additional professional support, both in the first year of dementia (65.2%) and in subsequent years (60.9% and 58.4%). In addition to the mainly practical types of support (e.g. day care and assistance with housekeeping) that persons with dementia already received, informal caregivers' needs for additional support mainly concerned advice about dealing with the behavior of the person with dementia and information about dementia and the supply of support. Informal caregivers of persons with initial symptoms of dementia additionally indicated a need for information about the availability of professional support in

Table 3. Types of Professional Support Used by Persons with Dementia (in Percentages)

	Stages of Dementia[a]				
Professional Support	**< 1 Year N=89**	**1-4 Years N=744**	**≥ 4 Years N=661**	**Total N=1494**	**p**
Day treatment, day care, meeting centre	38.2	49.9	50.2	49.3	0.10
Assistance with housekeeping	34.8	38.3	36.3	37.2	0.66
Assistance with personal care	32.6	35.6	37.2	36.1	0.64
Medical treatment	12.4	21.2	22.1	21.1	0.11
Consultations with a dementia counselor or counselor for the elderly	15.7	19.5	17.9	18.5	0.57
Case management	15.7	15.9	13.6	14.9	0.48
Number of persons receiving some kind of professional support	**< 1 year N=77**	**1-4 years N=684**	**≥ 4 years N=619**	**Total N=1406**	**p**
Receiving > 1 type of professional support	54.5	63.7	62.4	61.7	0.28

Note. The table does not indicate the frequency with which types of support were provided.
Differences between the stages of dementia are not statistically significant (chi-square test, p > 0.01)
[a]Evaluated by the informal caregiver.

Table 4. Informal Caregivers' Needs for Additional Professional Support in the Care for Persons with Dementia (in Percentages)

Needs for Additional Professional Support	Stages of Dementia[a]			Total N=1494	p
	< 1 Year N=89	1-4 Years N=744	≥ 4 Years N=661		
Advice					
- I need to know what to do when the person with dementia is afraid, angry or confused	21.3	25.0	21.2	23.1	0.22
- I need to know how to deal with the apathy of the person with dementia	14.6	18.4	15.2	16.7	0.23
- I need to learn how to cope with changes in the behavior of the person with dementia	16.9	15.7	11.5	13.9	0.05
- I need to know how to undertake activities with the person with dementia	18.0	13.6	9.5	12.1	0.01
- I need to know how to deal with aggression of the person with dementia	6.7	11.8	12.6	11.9	0.28
Information					
- I need information about the availability of professional support in the region	27.0	19.4	14.5	17.7	0.00*
- I need information about the legal regulations/allowances in case of admission to a nursing home or home for the elderly	12.4	14.8	14.7	14.6	0.83
- I need information about the progression of dementia	15.7	14.4	10.5	12.7	0.06
- I need information about the support offered by nursing homes	16.9	11.0	10.2	11.0	0.17
Emotional Support					
- I need someone to take away the feeling that I am the only one looking after the person with dementia	14.6	12.9	14.4	13.7	0.69
- I need someone to look after the person with dementia now and then	7.9	14.7	12.1	13.1	0.12
Practical Support					
- I need support with chores in and around the house (e.g. repairs, garden)	12.4	11.3	12.6	11.9	0.75

The questionnaire addressed a total number of 59 needs for additional support. This table reports the needs most frequently mentioned by informal caregivers.
*Difference between the stages of dementia is statistically significant (chi-square test, $p < 0.01$)
[a] Evaluated by the informal caregiver.

the region. This is in line with previous research [13, 22, 23], which suggests that informal caregivers' use of supportive services may be limited by their lack of awareness of available services. The variation, fragmentation and continuous changes in available services can cause informal caregivers to experience difficulties in finding the appropriate services [14].

Although the percentage of informal caregivers who experienced problems in caring for the person with dementia was not significantly higher in later stages of the dementia process, some specific problems do increase as the illness proceeds: loneliness and less contact with family, friends and acquaintances were problems more frequently mentioned by informal caregivers of persons who had had symptoms of dementia for a longer period of time [19]. In line with previous research [24], our results indicate that the social networks of informal caregivers are negatively affected by caring for a person with dementia for an extended period of time. Moreover, informal caregivers of persons in later stages of dementia more often considered the care for the person with dementia as physically too demanding, and they more often indicated that health problems may arise because the person with dementia has difficulties in communicating physical ailments.

LIMITATIONS

Informal caregivers who participated in the study were recruited during support and information meetings organized by the Dutch Alzheimer's Association and through professional care providers. Although this procedure enabled us to recruit informal caregivers of persons in various stages of the illness process, supportive services of this kind may be used mainly by informal caregivers who experience problems in caring for a person with dementia and/or who experience a need for additional support. This may have led to an overestimation of perceived problems and needs for additional support in our sample. On the other hand, informal caregivers who do not use such supportive services may also have no access to other forms of support. In this regard, our results may have led to an underestimation of informal caregivers' perceived problems and needs for additional support.

Our operationalization of the stages of dementia was based on informal caregivers' evaluations. This may have caused some bias, because informal caregivers may not always be able to evaluate adequately when the symptoms of dementia have occurred. Informal caregivers, however, are often involved in the care for the person with dementia more directly and for a longer period of time than professional caregivers. Therefore, their ability to evaluate when symptoms of dementia started to occur may sometimes be better than that of professional caregivers. Future research should investigate to what extent the evaluations of professionals and informal caregivers differ in this respect.

Due to the study's cross sectional design, we could not monitor individual changes in informal caregivers' problems, needs and service use over time. Longitudinal studies are needed to obtain a more complete picture of how informal caregivers' problems, needs and service use develop during the course of the illness.

CONCLUSIONS

Almost all informal caregivers experience psychosocial problems and support needs in both the initial and later stages of dementia. Therefore it appears to be important that nurses and other professionals involved in dementia care provide support to informal caregivers, education and coaching during the *entire* illness process. It is recommended that informal caregivers are provided with practical advice on how to cope with symptoms of dementia, on how to deal with the behavior of the person with dementia and that they receive more information about (early and advanced stages of) dementia and the supply of support. Nurses or case managers specializing in supporting informal caregivers and persons with dementia may play a role in providing such practical advice and information.

In addition, this study also revealed some differences between informal caregivers' problems and needs in the initial stage and the later stages of dementia. Addressing these differences may make it possible to tailor nursing care more closely to the needs of informal caregivers. Firstly, informal caregivers of persons with initial symptoms of dementia may be provided with information about the availability of professional support in the region. Websites providing customized advice about available care and welfare services may be useful in this respect [12].

Secondly, informal caregivers' social networks are negatively influenced by the prolonged care for a person with dementia. Offering respite care to informal caregivers of persons in later stages of dementia may reduce their caring duties and may thereby enable them to spend time maintaining their contacts with friends and relatives. Contacts with other informal caregivers of persons with dementia may also be important in this respect.

AUTHORS' CONTRIBUTIONS

Marieke Zwaanswijk conducted the conception and design of the study, data analysis and interpretation on the data, drafting and preparation of the manuscript. José M. Peeters and Adriana P.A. van Beek conducted the conception and design of the study, the interpretation of the data and consultation. Julie H.C.M. Meerveld did the acquisition of subjects and commentated on the findings of the study. Anneke L. Francke contributed to the conception and design of the study and the manuscript, supervision of analysis of the data and drafting the manuscript. José M. Peeters, Adriana P.A. van Beek and Anneke L. Francke reviewed the paper. All authors read and approved the final manuscript.

CONFLICT OF INTEREST

Authors declare that they have no conflict of interest by any means with respect to the instant research manuscript.

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