


The caregiving phenomenon and caregiver participation in dementia

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Background: Dementia presents barriers to the collaboration between individuals and the healthcare system. Caregivers perform multiple functions helping patients with basic and instrumental activities but also communicating and mediating the dyads' needs within the broader social group. Interventions focusing on caregivers show that caregiver burden can be reduced, improving patient outcomes in a cost-effective way, but the generalisation of these findings is limited by several factors such as low participation rates of caregivers in studies. There is a global push to increase patient participation in health care, but this can be difficult for patients with dementia. Caregiver participation has arisen as a substitute, but there is a lack of standardised definitions, goals and outcome measurement tools for this participation.

Methods: In 2015, the Swedish Association of Local Authorities and Regions commissioned a study on possibilities of increasing caregiver participation within the Swedish Dementia Registry (SveDem). This discussion paper updates and adapts that report, aiming to broadly

summarise the caregiving phenomenon in order to provide a backdrop for clinicians seeking to understand the legal, ethical and practical considerations of caregiver participation in dementia. Relevant literature on caregiver participation is presented, and its definition, extent and practical implementation are discussed.

Discussion: The Swedish legal framework compels care providers to facilitate patient and caregiver participation in dementia and provides support to caregivers through the local level of government, but further work is needed to clarify and define the extension and form that this participation must take in clinical practice. Advanced directives are one step in extending patient participation to the period of advanced dementia.

Conclusion: Little research exists on caregiver participation. There is a need to develop a framework for caregiver and patient participation to determine the extent, type and form that such participation should take in health care, research and quality initiatives pertaining to persons with dementia.

Keywords: caregiver, dementia, healthcare organisation, informal care, participation, patient rights, social care.

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Introduction

Dementia symptoms can disrupt the collaboration between patients and healthcare providers. For this

reason, focus often shifts to caregivers and relatives who become critical sources of information of premorbid cognitive level and personality of people with dementia, and help understand problems that escape the short meetings or tests administered in the clinic. Caregivers help complete scales of functional ability, dependence, neuropsychiatric symptoms, quality of life and mood.(1–4) Their impressions are often used in conjunction with a clinician's ratings.(1) A 2011 estimation for the United States described 14.7 million caregivers, where 45% assisted persons with dementia.(5)

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As a natural consequence to participation, many care systems are regulating the rights of caregivers and relatives in relationship to the care system. In Sweden, care providers are obligated by law to allow patients and relatives to participate in care.(6) The right of caregivers to receive support is also codified by law and is the responsibility of the local level of government. However, confusion exists around basic terminology: from a practical perspective, a caregiver is anyone who defines themselves as such, even if patients with dementia and caregivers are often in contradiction on what constitutes caregiving.(7) The criteria for defining a valid caregiver or proxy for a patient's participation in the care process are not established and are also culturally specific.(8, 9) Societal attitudes towards the respective roles of caregiver and care receiver vary immensely, and healthcare systems must find ways to support caregivers in a culturally appropriate and ethical manner. The framework for implementation of patient participation is unclear, particularly in cases where the ability to understand information, evaluate courses of action and facilitate one's own care is impaired, such as is the case in dementia. Caregiver participation extends patient participation when such direct involvement is no longer possible, but it leads to its own set of ethical and practical problems.

Caregiver burden is a frequent concern (10) but caregivers also experience satisfaction from caregiving work, although this aspect has been less studied.(11) Decreased caregiver burden and increased caregiver satisfaction contribute to caregiver health and delay institutionalisation for persons with dementia.(9) For this reason, strategies that facilitate collaboration between caregivers and the care system are being pursued. A number of instruments exist to assess caregiver burden.(12) Fewer methods exist to evaluate caregiver *participation* in the care process of persons with dementia, although interest in the subject has grown in the past few years.(13) Caregivers often refuse or withdraw from interventions targeted at them, although caregivers experiencing more burden are more likely to accept help.(13, 14) To some extent, most clinicians will conduct informal evaluations of caregiver participation during interviews with the patient and their relative, and most clinicians are on the lookout for caregiver burden, out of concern both for caregiver health and for increased risks for the person with dementia. However, the lack of formal evaluation tools is concerning. This discussion article presents some of the existing literature on caregiving with the objective of providing a backdrop for the concept of caregiver participation. We then discuss caregiver participation in an attempt to clarify the concept and define the challenges of implementing and developing this framework in research, quality improvement and care.

Methods

This discussion paper originates from a report commissioned by the Swedish Associations of Local Authorities and Regions concerning the possibility of implementing measures to increase caregiver participation in the Swedish Dementia Registry (SveDem). This registry was established in 2007 with the aim to increase quality and equality of dementia care throughout Sweden and has been extensively described in previous publications.(15, 16)

A literature search was undertaken. PubMed was used for a search which was last updated on 13 November 2017. Search terms used were 'caregiver AND participation AND dementia' with 311 hits, 'caregiver AND support AND dementia' (5731 hits), 'caregiver AND scales AND dementia' (921 hits) and 'caregiver AND scale AND dementia AND Sweden (39 articles)'. Relevant articles were examined and served to identify research groups focusing on this caregiving: contact with these research groups led to five additional articles, (11, 17–20) of which two were not indexed in PubMed. (17, 19) General Internet searches (Google; November 2017) in Swedish were used to identify relevant government guidelines on 'patient participation' and 'caregiving'. The breadth of the subject precluded a systematic approach given the resources available for this work.

Literature review

Caregiving

Caregiving can be defined as the purpose that the caregiver attributes to a behaviour, rather than by the behaviour itself.(7) For example, in patients with slighter cognitive impairments, most caregiving centres on protecting the patient's self-image and preserving the relationship between caregiver and care receiver. This protective caregiving is experienced as crucial by many caregivers and is their most significant source of stress.(7) Care recipients and caregivers often do not agree on what constitutes caregiving.(7)

As cognitive impairment becomes more severe, caregiving can grow to include instrumental activities of daily living (IADL), followed by basic activities of daily living (ADL) and supervision/surveillance to prevent injury. (7)

One conceptualisation divides caregiving into five categories as described by Bowers et al. in 1987.(7) *Anticipatory* caregiving would include lifestyle changes and behaviours taken 'just in case' or in anticipation of patient's future needs. This type of caregiving can occur from a distance and would include decisions on where to live or choosing salaried work that would allow

caregiving. *Preventive* caregiving includes more active monitoring and includes activities undertaken by the caregiver to secure the care recipient's well-being and health. Altering the physical environment to make it safer or asking a patient about symptoms would be included in this group. *Supervisory* caregiving is an active involvement by the caregiver and easier to recognise as caregiving by observers. It includes arranging and controlling the process of activities, such as setting out instruments and providing verbal cues so that a patient can perform an activity more or less independently.(7) *Instrumental* caregiving includes activities that are actually performed by the caregiver and is the focus of most research. However, caregivers consider it the least important of the caregiving they administer. By contrast, *protective* caregiving is experienced as the most demanding and difficult by caregivers and includes protecting the patient from consequences of the disease, often damage to the patient's self-esteem rather than physical health. For this reason, many caregivers might strive to perform care in a way that is not perceivable by the care recipient.(7)

Caregiving affects everyone: throughout the span of a lifetime, the vast majority of people will provide some caregiving.(21) One in twenty adults in Sweden over the age of 18 identifies themselves as a caregiver.(22)

Demographics

Caregiving has traditionally been 'women's work', and most caregivers in most countries are still female, with an European average of 59% women caregivers.(23) This may be changing.(24–26) In a recent Swedish study, the proportion of women was the same (55%) among caregivers and noncaregivers.(21)

The demographic characteristics of caregivers and their relationship to the care recipient vary between cultures.(27) Table 1 offers examples on the demographic make-up of caregivers and care recipients across regions and time periods. In Sweden, a 2008 study found that 57% of caregivers were women with an average age of 61, and most were children to the care recipient (67%).(25) Most caregivers worked full time (55%), while 29% were retired and 13% worked part time.(25) The mean number of monthly contacts was 30 if the caregiver was a spouse and 13 if the caregiver was a child. Another recent study supports this demographic make-up.(26) By contrast, in a multinational European study 70% of caregivers were women, with an average age of 61. Caregivers were consanguineous to the patient in 52% of cases, and 50% were employed.(11)

Caregivers are more frequent in the south than in the north of Europe, with Sweden being one of three countries with the lowest proportion of caregivers in Europe.(23) Furthermore, each caregiver in the south of

Europe provides a larger quantity of care.(23) At least part of the difference in Nordic countries is made up by a greater emphasis on formal caregiving. In one Spanish study, 77% of caregivers were women, 61% cared for a parent, and men became caregivers only for their spouse, in old age.(28) In one Polish study, 63% of caregivers were women, and 43% were caring for a parent.(20) In Sweden, 21% of caregivers lived with the care recipient, (25) compared to 80% in Poland.(20) This contrasts with an historical perception of caregiving that assumed that cohabitation was always necessary for a caregiving relationship.(7)

Differences within the country are also apparent. One study compared rural and urban caregivers in Sweden, finding that rural caregivers were more likely to be women.(24) Urban caregivers were more likely to report difficulties getting help from family and more likely to experience that the family left them alone. By contrast, rural caregivers experienced more financial issues, as did women caregivers. In both groups, children in caregiver roles experience more scheduling conflicts and caregiver esteem than spouse caregivers. In both urban and rural settings, caregivers experience high satisfaction from their role.(24)

The caregiver experience

Several factors influence the impact of caregiving on a particular individual. The severity of the patient's dementia, dementia type and accompanying symptoms is an obvious one, as is the support of the healthcare system.(29) Other issues are particular to the caregiver: financial status, social status, career, age, health, residential setting and relationship to the patient have all been identified as important.(24, 25, 30) So too are psychological factors, such as coping strategies(25) or positive subjective experience of caregiving, which could serve to decrease caregiver burden.(30)

One way of conceptualising psychological adaptation for successful coping to stressors is called sense of coherence. Sense of coherence expresses the extent to which one has an enduring confidence that challenges appearing in life are comprehensible, manageable and meaningful.(25) This is important because sense of coherence seems related to quality of life and health in caregivers. In a Swedish study, higher sense of coherence correlated with lower caregiver burden and better subjective perception of health, while age correlated with subjective health and sense of coherence.(25) Cultural aspects certainly play a role: in one comparison between Spain and Brazil, higher burden was reported in the latter country and the correlates with caregiver burden were different. Brazilian caregiver burden was associated with female caregivers and not attending day care, whereas in Spain higher burden was linked with living with the care

Table 1 Noncomprehensive comparison of demographic characteristics of caregivers and care recipients in different countries and time periods

Author	Bowers et al., 1987(7)	Andren et al., 2008(25)	Warchol-Biederermann et al., 2014(20)	de Labra et al., 2015(11)	Mavandadi et al., 2016(13)	Sousa et al., 2016(31)	Dahlrup et al., PhD thesis, study II 2015 (43)	Ruiz-Adame Reina et al., 2017(28)	Reed et al., 2017. GERAS study (46)	Germany	UK	China	Du et al. 2017(27)
Region	USA	Sweden	Poland	Spain-Poland-Denmark	USA	Spain	Brazil	Spain	France	Germany	UK	China	
Year	1987	2008	2014	2015	2010-2014	2016	2010-2011	2012	2010-2011	2017		2017	
N	27	130	151	-	290	146	128	778	418	549	526	766	
Caregiver													
Age	38-72 (range)	61	59	-	65 (SD 13; range 24-93)	61 (SD 15)	59 (SD 14)	58 (avg) SD	62 (SD 12)	66 (SD 12)	68 (SD 12)	60.5 (SD 12)	
Sex (% female)		57	63	70	75	77	78	77	62	68	62	63	
Relationship to care recipient													
Spouse (%)		20	55	Not consanguineous	48	49	49	29	62	68	68	32	
Child (%)		67	43	Consanguineous	52	51	56	61				63	
Other (%)		13	3	-	-	-	-	10				5	
Living in the same household (%)		21	82	-	67	75	74	30					
Care recipient													
Sex (female %)	-	70	-	-	-	78	77	53	62	50	54	56	
Age	62-97 (range)	85 (avg)	72 (avg)	-	-	78	77	Median	79 (SD 7)	75 (SD 8)	79 (SD 8)	80.9 (SD 8)	
						(SD 7)	(SD 7)	86 (Q1-Q3; 81-90)					

Year corresponds to conduction of study; if not available, year of publication is given. Age presented in means and/or range as given, rounded to full years
 N, number, %, percentage; SD, standard deviation.

recipient, young caregivers and attending day care.(31) In a study examining a multi-ethnic Asian population, caregiver burden was associated with the caregiver being younger and married.(32) Caregiver burden is more prevalent in carers of patients presenting more neuropsychiatric symptoms, or more comorbidities, and is greater in carers of patients with dementia with Lewy bodies (DLB) than Alzheimer's dementia (AD)(29) and in patients with the behavioural variant of frontotemporal dementia.(33, 34)

In addition to depressive symptoms and anxiety, caregivers experience grief.(20) Traditionally, grief is defined as an emotional response to a loss, such as death. However, caregivers for patients with dementia grieve the loss of their relative long before they die. It is the loss of personality and intellect, which is captured by the description of Alzheimer's disease as 'the long goodbye' in popular culture. In dementia, besides death, there are other inflection points that create a grief reaction in caregivers: thus, some authors have explored grief reaction before and after 'social death', the point at which the patient is no longer capable of meaningful interaction.(35) Scales have been developed to assess caregiver grief.(35) Feelings of grief appear related to the caregiver's perceived personal sacrifice, sadness and longing, isolation and lack of social support. (20, 35) Grief could be differentiated from depression and was associated with worse mental health and quality of life. (20) Furthermore, the caretakers' predeath experience may predict their adaptation to the care recipient's death.(35) Caregiver grief correlates inversely with family support.(35) Furthermore, caregiver grief is also a process that changes over time: in some studies, caregiver grief peaks around the GDS 3 of the patient's dementia process, the point of nursing home placement or the point of 'social death'.(35)

A large proportion of caregivers experience positive aspects of caregiving, such as the rewards or satisfaction derived from the caregiving relationship.(11) Different aspects contribute to these positive experiences, such as observing desirable outcomes in the patient, and experiencing caregiving as meaningful, satisfying and fulfilling. Several caregiver- and patient-related factors make these positive experiences more likely: a good relationship between caregiver and patient before the illness, being a caregiver voluntarily (as opposed to circumstance or family imposition), maintaining leisure time, caregiver not working outside of the home, caregiver resorting less to venting as a way of managing negative emotions, caregiver satisfaction with the social support received and lower caregiver burden.(11) The Caregiver Satisfaction Scale (CSS) was developed to measure these positive aspects. A multinational European study found that several demographic caregiver factors correlated with caregiving satisfaction: for example, being consanguineous to

the care recipient, and suffering lower levels of subjective burden. Surprisingly, increased severity of dementia in the care recipient, as measured by the GDS, increased the caregiver satisfaction. Neither the length of the caregiving relationship nor the number or hours of caregiving per week correlated with satisfaction.(11) Other studies have shown that it is possible for caregivers to experience both high burden and high satisfaction from caregiving, when subjective burden is coupled to a sense of competence.(11)

Caregiving is work. The needs of the care recipient evolve over time, and the caregiving relationship changes as the caregiver develops strategies and competence in different aspects of the process.(11) Furthermore, caregiving lasts a long time, with some studies suggesting average caregiving relationships of 64 months.(11) Thus, it is reasonable to talk about caregiving careers, with caregivers in the initial stages of the process experience different feelings and needs than more experienced caregivers.(36)

The caregiver spouse vs the caregiver child. The most frequent relationships between caregivers and care recipients are that of spouse or child to the patient. Distant relatives and friends can also be caregivers and may be more frequent in certain cultural settings.(8)

There are fundamental differences between the spouse and child caregiver. By definition, they belong to different generations with a bimodal distribution in age: spouse caregivers tend to be older, of similar average age to the patient, whereas child caregivers are often middle-aged.(26, 35) The proportion of women among adult children is higher.(35) Spousal caregivers may have more frequent contact with the patient,(25) live with the patient more frequently(22, 35) and may be more reliable for reporting certain kinds of symptoms.(37) Adult children caregivers are more likely to work outside the home and to experience scheduling conflicts.(35) Spousal caregivers are more likely to experience physical limitations that make caregiving difficult(35) and report more feelings of depression.(38) Spouses are more likely to be caring for a man (husband), while child caregivers are more likely to be caring for their mothers.(35)

A 2011 meta-analysis compared spouses, child and child-in-law caregivers, analysing 168 studies. (38) The patients cared for by child caregivers were younger than those cared for by spouses. Spouse caregivers provided more hours of caregiving but completed similar number of tasks than child caregivers, suggesting that child caregivers condense their support, since they are less likely to live with the patient. (38).

The psychological and social experience of caregiving also varies between these two groups. The experience of grief may differ, with spouses experiencing an increase in the items of worry and felt isolation in later stages of the

disease progression, while children experience a de-escalation of these feelings.(35) In one Swedish study, spouse caregivers spent more time with the patient and received less home-help services than child caregivers(39), which is a finding confirmed by international studies.(35) Spouses also experienced the same caregiver burden than children caregivers, but higher disappointment and isolation. In another Swedish study, higher caregiving burden was noted for spouses.(25) Again, this experience of caregiving may be culturally specific. International literature suggests that spouses might suffer higher burden from caregiving, might be more involved in caregiving and might resort to nursing home placement later in the disease process.(40) However, there were no differences between spouses and other caregivers in day care use. (40) In a Swedish setting by contrast, child caregivers were associated with longer times to nursing home placement, with daughters delaying placement longer than sons.(26)

Amount of time dedicated to caregiving. Time dedicated to caregiving is expected to vary between settings, depending on dementia severity, social expectations of care and supervision, and supplementation from formal care. In a Swedish study from the 90s, the weekly average time of assistance dedicated by caregivers was less than 10 hours for half of the caregivers included.(39) In a more recent Swedish study, the average time of informal care was around 11–14 hours per week.(26) By contrast in a 1998 Spanish study, most participants dedicated more than 10 hours to caregiving per day. (17) A European report showed that time dedicated to informal caregiving varies widely across Europe, ranging from the 1000 hours a year of help provided by Spanish adult children to their parents (600 hours in Greece and 400 hours in France) compared to 119 hours in Sweden.(23, 41) This shows that caution is warranted when comparing studies from different cultures and time periods.

Caregiving can be divided into different elements. One Swedish study had an exploratory phase which included home observation of 15 caregivers who lived with persons with moderate dementia. Caregiving was divided into surveillance/supervision, help in activities of daily living (ADL), instrumental activities (IADL) and other tasks. Average help for ADL was 2.5 hours per day, compared to about twice as much help for IADL (4.8 hours). The total caring time per day was about 16 hours, of which more than 8 hours were due to supervision/surveillance.(42) Other studies often do not define what is included in caregiver time; one might suspect that some of the great differences between studies are due to some not recognising supervision/surveillance as part of caregiving.

Dementia severity was associated with more total caregiver time and more time for ADL, but did not impact

IADL, presumably because all patients were cognitively impaired enough to require maximum help with more complex activities. (42) Some care must be taken when extrapolating the above results to larger populations. First, the sample was relatively small ($n = 15$) and all care recipients were in the same, moderate, stage of dementia. All caregivers in the study lived with the care recipients. As previously described, the demographics and characteristics of caregivers and care recipients vary widely, and this sample might not be representative of the caregiver experience.(42) Another recent Swedish study found that 20% of dementia patients received formal support more than once per week, while 68% received informal support in the same time frame, indicating that the care system does not absorb all the patient's caretaking needs. Most patients received formal and informal support for IADL, and fewer required help with ADL (62% formal and 79% informal).(43)

Because caregiving comprises so many different activities, it can be hard to measure caregiving time. Supervision in particular may severely limit a caregiver's quality of life, independently from the actual amount of help that a patient needs. Needing supervision is also one of the main reasons that patient with dementia is placed in full-time care facilities. The hours of allocated formal care must be accounted for to give a comprehensive description of the patient's need of assistance.

Costs and trade-offs of caregiving

The worldwide societal cost of dementia is estimated at US\$818 billion.(44) In 2016, in the United States informal care amounted to 18.2 billion hours, translating into US\$230.1 billion.(45) Caregiver time is the predominant resource driving total societal costs of caring for patients with dementia. (46) In a 2010 estimate, for a worldwide societal cost of dementia of \$422 billion, \$142 billion were due to informal care.(47) If help with instrumental activities was considered, the informal care costs rose to \$329.(47) These estimates assume 1.6 hours of daily caregiving for basic ADL or 3.7 hours including instrumental activities.(47) However, as we have previously seen, the reality of caregiving differs greatly between settings and dementia stages. The proportion of formal to informal care varies between settings, but higher Gross Domestic Product (GDP) tends to be associated with more formal care.(48) Particularly difficult is measuring the trade-offs between formal and informal care (49): presumably offering support to caregivers could increase their willingness to provide informal care and reduce formal care costs. This could conceivably increase the cost from informal care, which is harder to measure and might drive costs 'underground' and risk an underestimation of societal costs linked to dementia.(48) There is a relationship between the caregiver-care receiver dyad's

health and healthcare costs, with caregivers who experience higher caregiver burdens increasing their own use of healthcare use. (50) Previous research has shown that interventions to reduce caregiver burden can be effective, cheap and do not have collateral effects on healthcare costs.(50)

Part of the difficulty in measuring informal costs is that the distinction between direct costs (resources used) and indirect costs (resources lost) is equivocal in this context.(48) As far as costs represent use of caregiver time (which is a resource), they are direct, but since the market value of caregiver time is hard to ascertain, estimates resemble calculations for indirect costs.(48) These costs might appear as loss of productivity from caregivers balancing work and caregiving, loss of salary for caregivers forgoing work or reducing work hours in order to administer care, or loss of career opportunities and impact on family life. 'Women in the middle' caught between administering care to their children and their parents might be a particular example of this.(7)

There are large regional differences in costs of caring for patients with dementia. One multinational study including France, Germany and the UK prospectively evaluated costs and resource use over 18 months.(46) In this study, UK caregivers spent more time on instrumental ADL than French caregivers, who relied more on the formal care system, and the total social costs were higher in the UK. UK caregivers were also more likely to receive financial support, while having the lowest use of community care services. The authors concluded that the French Alzheimer Plan, with its emphasis on caregiver support and training may have contributed to French caregivers missing fewer days of work.

Discussion: Caregiver participation as a substitute for patient participation

Patient participation in care is important and can help improve safety and outcomes. In recent years, there has been ongoing work to increase and develop patient participation within the Swedish healthcare system.(6) However, most user-centred interventions require a reasonably good cognitive level and an ability to understand instructions,(51) making participation difficult in dementia. Different levels of patient participation can be considered: low participation appears in collective forms of participation, for example in registry research. Indirect participation consists of participation from a relative or caregiver, compared to individual participation, when the patient themselves participate. (6) Thus, caregiver participation could serve as a proxy for patient participation in cases of dementia.(52) Table 2 shows a list of aspects that are important to patients when participating in quality registries.

Table 2 Aspects that are important to patients

- | |
|--|
| 1. Relative to the patient |
| a. Respect for patient's values and opinions |
| b. Information, communication and training |
| 2. Relative to care |
| a. Organised and integrated care |
| b. Continuity of care |
| c. Accessible care |
| 3. Broader social aspects |
| a. Lifestyle |
| b. Emotional support |
| c. Engagement with family and friends |

Adapted from: Swedish National Registries. Guide to Patients' Participation in Quality Registries 2013 (52).

The Swedish legal framework compels care providers to facilitate participation and provides support to caregivers through the local level of government. How this facilitation of participation and how this support is given are however subject to interpretation and vary between settings. It is harder to provide clear guidelines for the concept of 'caregiver participation' than for medical interventions. Further work is needed to clarify and define the extension and form that this participation must take in practice and to what extent this requires direct participation of patients and/or caregivers.

There are ethical challenges to caregiving. Caregivers may negotiate to gain consent or get a patient to collaborate, or outright resort to coercion to administer caregiving.(53, 54) In practice, a patient's ability to provide consent may need to be constantly evaluated.(53) Proxy consent for research was found to be acceptable as long as the intervention was low risk.(55)

Caregivers normally participate by helping clinicians to obtain information and by giving their opinion on quality of care. A number of scales for relatives of patients with dementia cover neuropsychiatric symptoms(1), dependency, (2) quality of life and mood(3). However, there are no formal scales measuring the level of caregiver participation. Although care systems encourage caregiver participation, most fail to define it. Depending on the degree of cognitive impairment, it may be impossible to distinguish between patient and caregiver participation. A recent qualitative study attempted to identify caregiver's experience on patient participation in home-based care. Conflicts arose when negotiating consent from a patient with dementia: on the one hand, caregivers identified dementia patients as confused or 'not knowing what was best for them'. Despite this, they preserved the patient's autonomy and consent, sometimes resorting to persuasion or enlisting other family members for help. Caregivers overstepped these boundaries and actively opposed the patient when they perceived the patient's

Table 3 Examples of effects of caregiver participation on patient outcomes

Patients experience improved episodic recall when caregivers participate in cognitive training with the patient with dementia	Neely et al. 2009(12)
Caregiver attitudes on physical activity predict patient participation in exercise	O'Connell et al. 2015(13)
Interventions that support caregivers by acting on both caregiver and care recipient are more effective than those which focus only on the patient	Thinnes et al. 2011(14)
Caregiver training in occupational therapy results in higher participation of AD patients, greater quality of life and satisfaction	Padilla et al. 2011(15)
A psychosocial intervention on caregivers including education, information and a support group resulted in better understanding of patient's symptoms. This improvement was sustained over 18 months.	Dahlrup et al., 2015 (21)

actions as dangerous. (53) In Sweden, from 1 July 2017, a new law allows patients to assign power of attorney for specific aims in advance (*Lag om framtidsfullmakter*, SFR 2017:310): this allows patients to make decisions and participate in their care while they still can, and the power of attorney goes into effect only when the patient can no longer manage the specific affairs described in the power of attorney. Table 3 shows examples of effects of caregiver participation on patient outcomes.

Dementia care networks have been established in several countries to provide support for persons with dementia and their families. These networks have been shown to reduce caregiver burden(56) and may influence societal costs.(46) It may be more meaningful to actively engage both caregiver and care recipient in interventions, with the care recipient's participation occurring to the extent to which their illness permits. Caregiver-patient dyads can participate in this way in the individual patient's care and in quality of care improvement initiatives as well as in research. This is a situation that is already frequent in clinical practice and which can be utilised and given a more formal voice in future projects pertaining to the dementia community.

Conclusion

Caregiving for patients with dementia is a frequent phenomenon, but the demographic make-up of caregiver cohorts varies between regions and is subject to changes over time. The percentage of caregivers that exist in any society and the type of caregiving they administer also depend on the amount of formal care that patients with dementia can receive. Caregiving is complex and difficult to measure. The amount of time dedicated to caregiving varies greatly between studies, partly due to some including supervision in addition to help with basic and instrumental activities. Several care systems are working towards improved patient participation in care, which is a legal requirement in Sweden. This can be difficult in patients with dementia, where caregiver participation is perhaps a more feasible alternative at least in the later

stage of the dementia process. However, little research exists on caregiver participation. There is a need to develop a framework for caregiver and patient participation to determine the extent, type and form that such participation should take in care, research and quality initiatives pertaining to persons with dementia. Further work is needed to establish a concrete definition and outcomes for caregiver participation in order to create measurable goals for implementation.

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Author contributions

Sara Garcia-Ptacek wrote the manuscript draft and conducted revisions. Beth Dahlrup revised for scientific content and approved the final manuscript. Ann-Katrin Edlund revised for scientific content and approved the final manuscript. Helle-Wijk revised for scientific content and approved the final manuscript. Maria Eriksson revised for scientific content and approved the final manuscript.

Ethical approval

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