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How transitions in dementia care trajectories affect health problems in partners: a longitudinal analysis with linked health and administrative data

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Abstract

Objectives: To evaluate whether the prevalence of health problems in cohabiting partners of people with dementia differs between the year before and the year after three transitions: the diagnosis of dementia, institutionalization and the death of the person with dementia.

Methods: Individuals with dementia and their partners were identified on the basis of data in the electronic health records (EHRs) of 451 Dutch general practices. EHRs were also the data source on their health problems, which were linked to the Dutch population registry and health administration data with demographic characteristics, date of institutionalization and date of death. Differences in the prevalence of sixteen groups of health problems and of specific health problems in partners during the year before and the year after the three transitions were examined using generalized estimating equation (GEE).

Results: 1110 partners of persons with dementia were identified. Problems related to the illness and/or loss of the person with dementia, were significantly more prevalent in the year after the dementia diagnosis (32% vs 17%) and in the year after the death of the person with dementia (59% vs 41%) than in the years before. Unspecified health problems were more prevalent in the year after the diagnosis than in the year before (30% vs 22%). After institutionalization, an increase was found in digestive problems and urological problems (30% vs 18% and 24% vs 17%).

Discussion: Transitions during the dementia care trajectory, namely the diagnosis, institutionalization and death of the person with dementia, significantly impact the cohabiting partner's health.

Introduction

The number of people with dementia is increasing worldwide, placing a huge demand on family caregivers, a role that is most often fulfilled by a partner or an adult child (Brodaty et al., 2009). Several review studies indicate that providing family care to a person with dementia can have a negative impact on both mental and physical health outcomes in family caregivers (Bleijlevens et al., 2015; Pinquart et al., 2007; Schulz et al., 2008).

Dementia is a disease that is characterized by different stages, from the early symptoms to the end of life (Fortinsky et al., 2014). During these stages, persons with dementia generally undergo distinguishable transitions, with consequences for the care that they need. While there is no single widely accepted classification of standard transitions in the dementia trajectory (Fortinsky et al., 2014), most of the available classifications include the diagnosis of dementia and changes in care settings (Fortinsky et al., 2014; Rose et al., 2012).

The theoretical framework most commonly used to guide caregiving research is based on the stress and appraisal paradigm (Boerner et al., 2004), and includes the conceptual model of carer stress and burden as published by Sørensen and colleagues (2006). This model describes the association between stressors and caregiver health outcomes. The care situation, which includes the care intensity (for example, the hours spent on providing care), operates as a primary stressor in this model (Sørensen et al., 2006). Transitions in the dementia trajectory affect the care situation (Fortinsky et al., 2014) and are therefore expected to indirectly affect health outcomes in family caregivers, according to this model. Furthermore, this model assumes that health outcomes can be affected, both directly and indirectly, by background characteristics such as the caregiver's sex and the type of caregiver (whether this is for instance a friend, a partner or an adult child) (Sørensen et al., 2006).

The literature concerning the effects of specific transition points in the dementia trajectory on the health of caregivers is not unequivocal. For instance, some studies show that the dementia diagnosis can make family caregivers, especially partners, feel very insecure about the future (Bramble et al., 2009), increasing stress levels and thereby negatively impacting their health (Miles et al., 2016; Pinquart et al., 2007; Mausbach et al., 2007; Perkins et al., 2013). On the other hand, other studies show that a diagnosis can lead to feelings of relief or acknowledgement and can help family caregivers to arrange timely care and support, thereby reducing stress (Prince et al., 2011).

The move of a person with dementia to a long-term care facility has been described as one of the most distressing experiences in the dementia trajectory for family caregivers (Fortinsky et al., 2014; Davies et al., 2006). Institutionalization can be accompanied by feelings of guilt, anger, anxiety and depression (Schulz et al., 2004; You et al., 2014). What is more, institutionalization of the person with dementia does not necessarily reduce the care burden in family caregivers, but rather leads to a shift in roles from providing care to monitoring care and serving as an advocate for the person with dementia (Gaugler et al., 2005; Nikzad-Terhune et al., 2010). Other studies suggest, however, that the move to a long-term care facility positively affects the mental and physical health of family caregivers, as it relieves them, especially cohabiting partners, from many care duties (Gaugler et al., 2009, 2010; Mausbach et al., 2007).

Since there is no treatment currently available to cure dementia, dying with or as a consequence of dementia is inevitable. Yet it is still not clear what effect the death of a person with dementia has on health outcomes in their family caregivers (Schulz et al., 2003). Family caregivers can on the one hand feel relieved (Stahl et al., 2019) and research shows improvements in health practices in family

caregivers after the loss of the person with dementia as well as a reduction in depression (Schulz et al., 2003). On the other hand, they often experience feelings of grief, as well as stress from having to arrange administrative matters (Brodsky et al., 2009).

Recapitulating, it remains unclear whether transition points in the dementia trajectory have a positive or negative impact on health outcomes in family caregivers. Insights into the impact of transition points on a broad range of both mental and physical health outcomes could help healthcare professionals to recognize indicators of overload in family caregivers looking after persons with dementia. Focusing on health problems before and after transition points can provide an understanding of when family caregivers have the highest risk of overload and health problems. These insights could help healthcare professionals act in good time to provide support for family caregivers of persons with dementia. Since partner caregivers have a higher risk of being overburdened than other caregivers of people with dementia, it is especially important to identify overload and health problems in good time in this group (Pinquart et al., 2003; Wolff et al., 2006; Swinkels et al., 2019).

The current study therefore focuses on the impact of transition points on the health of partners of persons with dementia. The aim of the study is to examine whether there are differences in the prevalence of a wide range of physical and psychosocial health problems in cohabiting partners of persons with dementia between: a) the year before and the year after the diagnosis of dementia; b) the year before and the year after the person with dementia moves to a long-term care facility; c) the year before and the year after the death of the person with dementia. Differences between male and female partners are taken into account, since women providing care to a partner with dementia are generally more burdened than male caregivers (Swinkels et al., 2019; Pinquart et al., 2006; Yee et al., 2000).

The novelty of this study is its design, which is based on the use of linked health and administrative data, making it possible to study the effects of transition points in the dementia trajectory on a broad range of mental and physical health outcomes as recorded by a GP. This has not been done before and differs from the many studies that used questionnaires to assess – mainly psychological – health outcomes. Yet the conceptual model of carer stress and burden implies that stress in caregivers due to the care situation (e.g. transitions), could affect physical as well as mental health outcomes.

Methods

Electronic health record (EHR) data from GPs were linked to national administrative databases and the resulting datasets were analysed. The data covered the year before and the year after the diagnosis of dementia, the year before and the year after the move to a long-term care facility, and the year before and the year after the death of the person with dementia.

Data resources

GP data

Data on psychosocial and physical health problems were retrieved from the EHRs of Dutch GPs who participate in the Nivel Primary Care Database (Nivel PCD) (<https://www.nivel.nl/en/nivel-primary-care-database>). The Nivel PCD holds pseudonymized data on approximately 1.7 million individuals (10% of the Dutch population); the data are routinely recorded in EHRs by a nationally representative network of 451 GP practices, spread evenly across the country.

In the Netherlands, GP acts as a family doctor and a „gatekeeper“ to hospital care or other care provided by medical specialists. The GP plays a key role in the standard care for people with dementia and their partners. Partners are normally registered with the same general practice as the

person with dementia. In principle, all Dutch residents living at home (rather than in an institution) are registered with a general practice. Therefore the morbidity reported in general practices is representative for the morbidity of community-dwelling people in the Netherlands in general.

The databases include data on the number of consultations, diagnoses, prescriptions and referrals of all the patients who are registered with the participating GP practices. Contact diagnoses are coded using ICPC-1 (International Classification of Primary Care) (Lamberts, 1987) and grouped into disease episodes (Nielen et al., 2019). GPs receive feedback on the quality of their recording and support in coding (Verheij et al., 2018; van der Bij et al., 2013). The dementia diagnosis is often made by a specialist from a memory clinic or a hospital and copied into the GP's EHR system.

Administrative data

Data on socio-demographic characteristics of the person with dementia and their cohabiting partner, the date of institutionalization of the person with dementia and the date of their death were obtained from administrative data sources made available for research by Statistics Netherlands (Centraal Bureau voor de Statistiek, CBS). This is the governmental institution that is responsible for processing statistical population data in the Netherlands. Sociodemographic characteristics and the date of death came from the Municipal Personal Records Database, which covers all persons residing in the Netherlands. The date of institutionalization came from the administrative data for the Dutch national long-term care insurance scheme, which covers all institutionalizations (in nursing, residential or psychiatric homes) of all Dutch adults.

Study population

In the Nivel Primary Care Database, we identified all partners of persons born in 1965 or before with a recorded dementia diagnosis (ICPC code: P70) between 2008 and 2015. Partners were identified and included based on the following criteria: not having a recorded dementia diagnosis between 2008 and 2015, living at the same address as the person with dementia, living in a household of ≤ 5 persons at the same address, and having an age difference with the person with dementia ≤ 20 years. We excluded individuals in a household of more than 5 persons at the same address as this could imply that the person lives in a residential care home. Also, pairs of individuals were excluded if the age difference was more than 20 years as it is then more likely that the second person is not the partner of the person with dementia. Households with more than one person with dementia were also excluded. Partners were included in the analyses if they were registered with their GP for the complete year before and the complete year after the transition point in question.

Outcomes

Prevalence of psychosocial and physical health problems in the partner

The prevalence of psychosocial and physical health problems was defined as the presence of a morbidity or symptom as recorded in the partner's EHR during a specific year in the period 2008-2015. Dutch GPs encode morbidities and symptoms in the EHR system using the nationally adopted ICPC classification system (which is analogous to the International Classification of Diseases (ICD) coding system). There are a total of 685 different predefined ICPC codes, which are clustered into 17 ICPC chapters reflecting overarching health categories. An overview of these specific codes and the 17 ICPC chapters can be found in: http://docpatient.net/3CGP/QC/ICPC_desk.pdf. To give an example, one of the ICPC chapters is labelled 'social problems'. This chapter includes problems (codes) that relate to social issues, such as 'unemployment problems' and 'relational problems', but also 'problems with the illness of a partner' and 'problems with the loss or death of a partner'. Since

there are 685 specific ICPC codes, we could not test differences in all of these codes (due to the issues associated with multiple testing and the very small numbers for individual codes). Therefore it was decided to perform tests per ICPC chapter first (excluding the chapter on pregnancy) and only zoom in on specific codes within a chapter if that chapter showed a significantly higher or lower prevalence ($p \leq 0.01$) after a transition.

Socio-demographic characteristics

The following socio-demographic characteristics of the persons with dementia and their partners were described: age, sex and migration background. The migration background was classified into two categories: non-Western migration background (Surinamese, Antillean, Aruban, Moroccan, Turkish or other non-Western migration background) and Western background (Dutch or other Western migration background).

Date of institutionalization and date of death

The date of institutionalization and date of death of the persons with dementia were used to determine whether and when a person with dementia moved to a long-term care facility or died.

Data linkage

The GP data were pseudonymized at source (i.e. the GP practice) and transferred securely through a trusted third party to Statistics Netherlands, where the data linkage with the administrative data was performed. Pseudonyms were based on the citizen service number (a unique number assigned by the state to every citizen in the Netherlands), or on a combination of date of birth, sex and postal code. The pseudonymized data were made available to the researchers in a secured environment under strict privacy conditions.

Statistical analysis

Using the linked dataset, the prevalence of the 16 overarching health categories (the ICPC chapters) per year was calculated for the partners and described for the year before and the year after the diagnosis of dementia, and the institutionalization (where relevant) and the death (where relevant) of the person with dementia.

To examine whether the prevalence of health problems increased or decreased significantly after these three transitions, generalized estimating equation (GEE) models were fitted. GEE models take into account the correlation of different (repeated) measures within subjects (in the current study the measures of the partner's health before and after a transition).

For each of the 16 ICPC chapters, three GEE models for binary response variables were fitted: one to examine differences in prevalence between the year before diagnosis and the year after; one to examine differences in prevalence between the year before institutionalization and the year after; and one to examine differences in prevalence between the year before the death of the person with dementia and the year after.

Since we were interested in the effects of the single transition points and because some partners faced multiple transitions within a year, in the GEE models we controlled for other possible transition patterns: i.e. being diagnosed and institutionalized in the same year, being diagnosed and dying in the same year, or being institutionalized and dying in the same year. Furthermore, as we expected the partner's sex to have an effect on the prevalence of health problems in partners, sex was included as an explanatory variable in the GEE models.

In addition, GEE models were fitted for all the specific health problems (specific ICPC codes) that fell within those overarching ICPC chapters with a significant difference in prevalence before and after a given transition ($p \leq 0.01$). Only significant differences ($p \leq 0.01$) in specific health problems that

occurred in at least 5% of the partners were considered relevant and only these differences are therefore reported. Because of multiple testing, a significance level of $p < .01$ was applied rather than the usual significance level of .05. All analyses were conducted in SPSS version 15.

Ethics

This study has been approved by the ethics committee of the VU University Medical Center and is in accordance with the governance code of the Nivel Primary Care Database, filed under number NZR-00315.063. As pseudonymized data were used that were collected for routine administrative registration purposes, the informed consent of the participants was not necessary. Patients were informed by their GP about the use of their pseudonymized health data and were given the opportunity to object.

Results

Sample characteristics

The data of a total of 1110 partners of persons with dementia were included in at least one of the analyses. Of this group, data on 1071 partners were included in the analyses to compare the prevalence of health problems before and after the diagnosis of dementia. Data on 231 partners were included in the analyses to compare the prevalence before and after institutionalization. Data on 145 partners were included in the analyses to compare the prevalence before and after the death of the person with dementia.

The partners were mostly women (58.9%) and had a mean age of 75. The vast majority had a Dutch or Western migration background (97.2%); see Table 1. The persons with dementia were mostly men (57.4%), had a mean age of 78 and overwhelmingly had a Dutch or Western migration background (97.0%).

Death and moving (for example to a nursing home) were the most important reasons for partners ceasing to be registered with a GP for the complete year before and the complete year after the transition point in question and therefore not being included in the analyses.

A total of 10.5% out of the 1110 included partners faced the diagnosis and institutionalization of the person with dementia within the same year, 7.4% faced the diagnosis and death of the person with dementia within the same year and 5.1% faced the institutionalization and death of the person with dementia within the same year.

[Table 1]

Differences in the prevalence of health problems in the partner before and after the dementia diagnosis of the person with dementia

Figure 1 indicates that musculoskeletal problems (ICPC chapter L) are the most prevalent category of health problems in partners, both before and after the dementia diagnosis.

Furthermore, it shows that general or unspecified health problems (ICPC chapter A) were significantly more prevalent in partners of persons with dementia in the year after the dementia diagnosis than in the year before the diagnosis (30% vs 22%; odds ratio (OR)=1.56 (95%CI=1.31-1.86); $p < .01$). More specifically, within this ICPC chapter, the ICPC code for „no disease“ was more prevalent in the year after the diagnosis than in the year before the diagnosis (10.4% vs 7.2%; OR=1.49 (95%CI=1.13-1.97); $p < .01$).

In addition, social problems (ICPC chapter Z) were significantly more prevalent in the year after the diagnosis than in the year prior to the diagnosis (32% vs 17%; OR=2.54 (95%CI=2.08-3.10); $p < .01$). Partners who had faced the diagnosis and the death of the person with dementia within the same

year had significantly more social problems than persons who did not face these two transitions within a year (OR=2.37 (95%CI=1.57-3.58); $p<.01$). Furthermore, social problems were more prevalent in female partners than in male partners (OR=1.51 (95%CI=1.20-1.90); $p<.01$).

The specific ICPC codes within the social problems chapter that were more prevalent in the year after the diagnosis compared to the year before comprised „problems with the illness of the partner“ (17.6% vs 8.7%; OR=2.26 (95%CI=1.76-2.89); $p<.01$) and „loss or death of the partner“ (9.1% vs <1%; OR=43.79 (95%CI=13.82-138.77); $p<.01$). For the former outcome we found that this was more prevalent in female partners than in male partners (OR=1.48 (95%CI=1.11-1.98); $p<.01$). For the latter outcome we found that partners who had faced the diagnosis and the death of the person with dementia within the same year had a higher prevalence of problems related to the loss or death of the partner than partners who did not face these two transitions within the same year (OR=49.31 (95%CI=22.04-110.31); $p<.01$).

[Figure 1]

Differences in the prevalence of health problems in the partner before and after institutionalization of the person with dementia

Figure 2 shows that both in the year before institutionalization and in the year after, social problems (ICPC chapter Z) were the most prevalent category of health problem in partners. No significant difference was found in the prevalence of social problems before and after institutionalization, but we did find that partners who faced the institutionalization and death of the person with dementia within the same year had significantly more social problems than partners who did not face these two transitions within a year (OR=2.49 (95%CI=1.72-3.63); $p<.01$).

Furthermore, digestive problems (ICPC chapter D) (30% vs 18%; OR=1.99 (95%CI=1.34- 2.95); $p<.01$) and urological problems (ICPC chapter U) (24% vs 17%; OR=1.63 (95%CI=1.13-2.36); $p<.01$) were significantly more prevalent in partners in the year after institutionalization than in the year before the transfer. No specific health problems within these chapters were significantly more prevalent in the year after institutionalization compared to the year before.

[Figure 2]

Differences in the prevalence of health problems in the partner before and after the death of the person with dementia

Figure 3 shows that in the year before the death of the person with dementia, musculoskeletal problems (ICPC chapter L) were the most prevalent type of health problem in partners. In the year after the death of the person with dementia, social problems (ICPC chapter Z) were the most prevalent type of health problem.

Partners had significantly more digestive problems (ICPC chapter D) (32% vs 20%; OR=1.99 (95%CI=1.32-2.98); $p<.01$) and more social problems (59% vs 41%; OR=2.14 (95%CI=1.34-3.41); $p<.01$) in the year after the death of the person with dementia compared with the preceding year. No specific health problems within these chapters were significantly more prevalent in the year after death compared to the year before.

Furthermore, partners who had faced the institutionalization and the death of the person with dementia within the same year had more social problems than partners who did not face these two transitions within a year (OR=2.19 (95%CI=1.31-3.67); $p<.01$). The specific health code „problems with the loss or death of the partner“ was more prevalent (51% vs 12%; OR=8.04 (95%CI=4.32-14.97); $p<.01$) and „problems with the illness of the partner“ was less prevalent (<10% vs 23%; OR=0.18 (95%CI=0.08-0.39); $p<.01$) after the death of the person with dementia than in the year

before. 'Problems with the illness of the partner' was more prevalent in partners who had faced the institutionalization and the death of the person with dementia within the same year than in partners who did not face these two transitions within a year (OR=3.70 (95%CI=1.53-8.97); $p < .01$).

[Figure 3]

Discussion

Reflection on the main findings

This study provides insight into changes in the prevalence of health problems in cohabiting partners of persons with dementia between the year before and the year after three transitions in the disease trajectory: the point when the dementia diagnosis was recorded in the GP's EHR system, the point when the person with dementia moved to a long-term care facility, and the death of the person with dementia.

We found that only the ICPC codes „problems with the illness of the partner“ and „no disease“ were more prevalent after the diagnosis than before. This implies that the diagnosis of dementia does not lead directly to an increase in physical health problems in the partner of the person with dementia. On the other hand, we found a higher prevalence of physical health problems after institutionalization of the person with dementia than before institutionalization, including digestive and urological problems. After the death of the partner, we mainly found „problems with the loss or death of the partner“. Furthermore, an increase in the prevalence of digestive problems was found.

The increase in physical health problems after institutionalization and death of the person with dementia could be an indication of stress, or it may be because the partner now had more time to visit the GP for their own health problems as they were no longer spending time caring for the person with dementia (or no longer spending as much time).

This latter explanation relates to the pragmatics of care provision, which is one component of caregiving. However, our data did not offer insight into the extent to which family caregivers were engaged in the pragmatics of care provision.

Since the family caregivers in our study were all cohabiting partners of persons with dementia, it can be assumed that these caregivers were exposed to the decline and suffering of the person with dementia, which is a second component of caregiving. This component is likely to cause stress and possibly lead to an increase in physical health problems.

Although this hypothesis corresponds with the model of Sørensen and colleagues (2006), we did not find a change in ICPC codes specifically for stress. Yet our data showed that partners contacted their GP more often after the person with dementia was institutionalized and after the loss of the person with dementia than in the years before (data not shown).

No significant differences were found with respect to psychological problems (ICPC code P) before and after transitions. Previous research has indicated that depression in particular is likely to be more prevalent in family caregivers after the partner moves to a long-term care facility (Schulz et al., 2004; You et al., 2014). The current study was based on coded information on symptoms and diagnoses as recorded in GPs' electronic health records. GPs may be likely to label mental health problems in partners of persons with dementia as 'problems with the illness of the partner'.

Furthermore, our study focused specifically on the cohabiting partners of persons with dementia (usually the spouse). Our expectations regarding the effects of transitions in the dementia trajectory on health outcomes in partner were based on studies that often included all family caregivers, which could for instance refer to adult children as well (e.g., Schulz et al., 2004; You et al., 2014; Davies et al., 2006). Combining the care for a parent with dementia with a job and/or the care for a separate

household might lead to more stress and additional health problems than in the case of a retired person caring for a cohabiting spouse with dementia.

In addition, in the Netherlands, cohabiting partners who care for a person with dementia receive support from home care services, dementia case managers, their GP and often other family members or friends. Perhaps this support from various sources helps prevent adverse health outcomes after transition points in the dementia trajectory.

We did find more social problems related to the illness or the loss of the person with dementia after the diagnosis and after the death of the person with dementia than before. Problems with the illness of the person with dementia were least prevalent in the year before the diagnosis and most prevalent in the year after the person moved to a long-term care facility. This finding supports the view that taking care of a partner with dementia is especially burdensome in the later stages of the disease, when it becomes increasingly difficult for partners to take care of their loved one with dementia and moving the person with dementia to a long-term care facility becomes inevitable.

In addition, we found that facing the diagnosis of dementia and/or the institutionalization of the person with dementia within the same year as the death of the person with dementia has consequences for the prevalence of social problems in partners. This prevalence was higher in such cases than in partners who did not face multiple transitions within a year. In particular, facing the death of the person with dementia in the same year as other transitions seems to affect the prevalence of social problems. This finding implies that having to cope with multiple transitions within a year increases the need for advice or support in partners of persons with dementia.

Interestingly, we did not find many differences between male and female partners in the prevalence of health problems. Only with respect to 'problems with the illness of the partner' did we find a higher prevalence in female partners than in male partners in the year prior and the year following the diagnosis of dementia.

It is also notable that we did not find more relational problems or problems with the behaviour of the partner after the diagnosis, two other codes that fall within the ICPC chapter of social problems. It could be that these problems are in fact present but are being categorized as problems with the illness of the partner by GPs

Furthermore, as we found no significant differences with respect to the specific health problems (individual codes) within the overarching ICPC chapters of urological and digestive problems, this suggests that there is great diversity in the specific nature of such health problems among partners of persons with dementia.

Strengths and limitations

An important strength of this study is that a large group of partners of persons with dementia was followed for at least two years. In addition, a wide range of psychosocial and health problems were examined using routinely recorded health data that were linked to administrative data. This linkage made it possible to determine not only the date of diagnosis as a transition point, but also the date of institutionalization and the death of the person with dementia.

A limitation of this study is the assumed under-registration of dementia in Dutch primary care, which means that we possibly did not include all people with dementia; we only included the people who had a registered diagnosis.

Another limitation is that we made use of GPs' EHRs to obtain information on health problems. People with health problems might not always visit their GP, so the prevalence of health problems as found in the current study might be an underestimation. On the other hand, the Netherlands has a dense network of GP services, which are free of charge, and the GP is the first point of contact when people face health problems. A referral from a GP is needed for access to specialist care.

The present study shows that health problems in partners are often categorized by the GP as 'problems with the illness of the partner' or 'problems with the loss or death of the partner'. Since

these problems are not further specified in GPs' EHRs, there is a lack of insight into the kinds of health problems that are being recorded in these categories.

Because of our research design, it was not possible to obtain insight into how partners themselves experienced the transitions. More insight into this aspect could have helped the interpretation of the findings. A suggestion for future studies on the effects of transitions in the dementia trajectory is therefore to combine qualitative and quantitative research.

Finally, a limitation of the current study is that no comparison was performed with a control group, which complicates the attribution of changes in health outcomes to transitions rather than to ageing.

Conclusion

Transitions in the dementia trajectory, namely the diagnosis, institutionalization and death of the person with dementia, seem to increase the prevalence of specific types of physical and mental health problems in cohabiting partners of persons with dementia. This is mainly reflected in an increase in general or unspecified health problems, digestive problems, urological problems and problems with the illness or loss of the person with dementia. GPs should be alerted when they see these types of problems in partners of patients with dementia so that they can offer timely support. Partners might be in particular need of advice or support during these transition phases.

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Tables and figures

Table 1 Characteristics of the included partners and persons with dementia

	Partners	Persons with dementia
N	1110	1110
Female, %	58.9	42.6
Age at moment of inclusion, mean (SD); median	75,1 (8,4); 76,0	78,2 (7,8); 79,0
Age categories, %		
under 65	11.7	5.8
65 - 74	32.5	25
75 - 84	43	49.9
85 and above	12.8	19.2
Migration background, %		
Western	97.2	97

Figure 1 Health problems in partners of persons with dementia before and after the diagnosis dementia

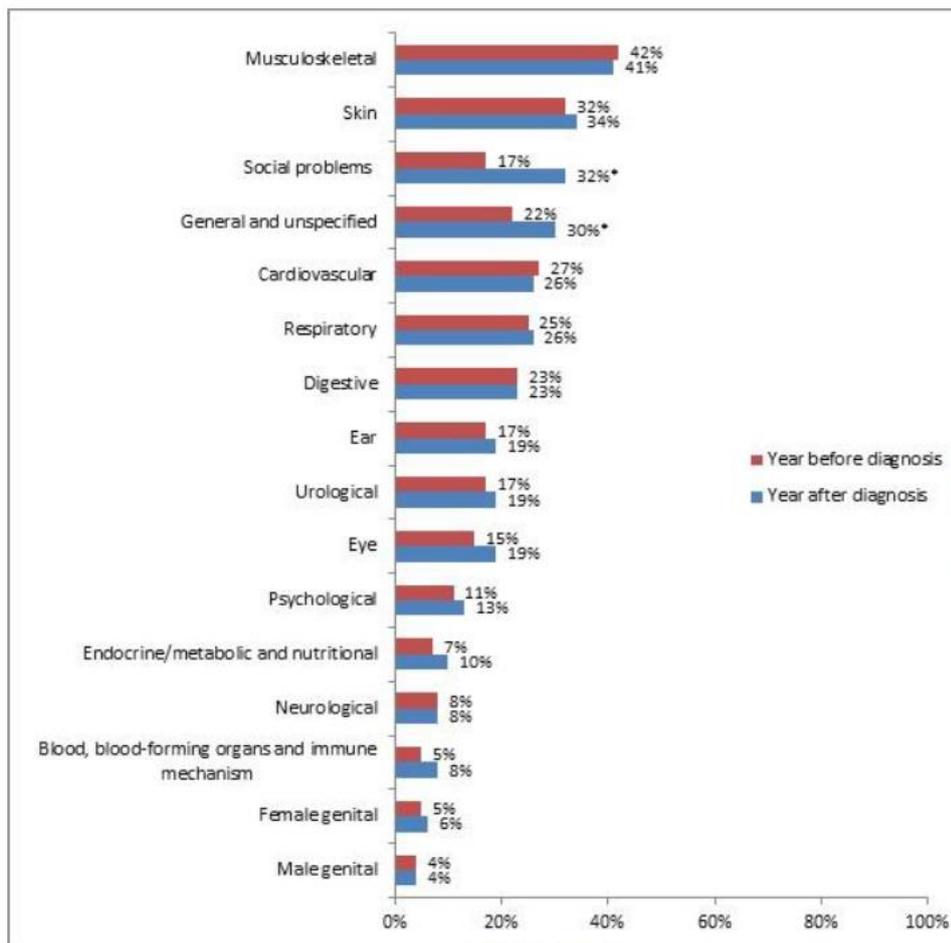


Figure 2 Health problems in partners of persons with dementia before and after institutionalization

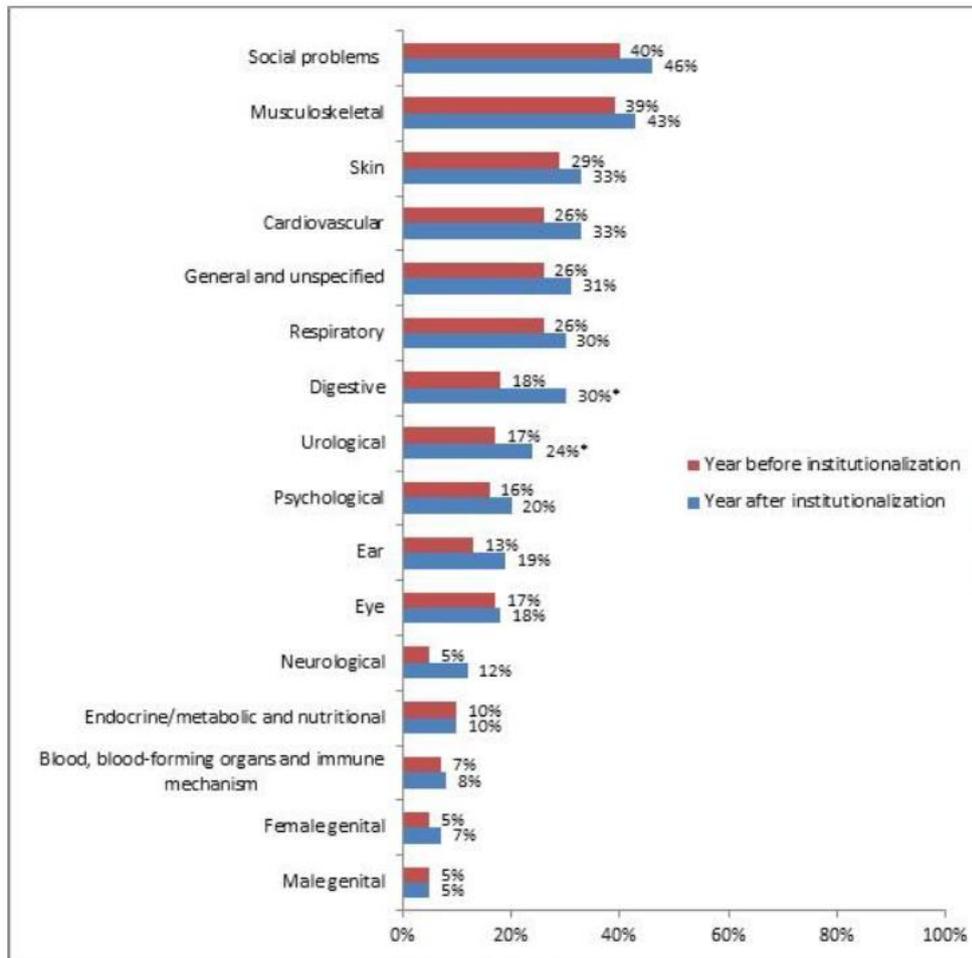


Figure 3 Health problems in partners of persons with dementia before and after the death of the person with dementia

