Prevalence of health problems and health-care use in partners of people with dementia: longitudinal analysis with routinely recorded health and administrative data

Iris van der Heide[a], Marianne Heins[a], Robert Verheij[a], Hein P.J. van Hout[b], Anneke Francke[a, b], Karlijn Joling[b],

[a]   Nivel, Netherlands Institute of Health Services Research, Utrecht, The Netherlands;
[b]   Amsterdam Public Health Research Institute, Amsterdam UMC, location VU University Medical Center, Amsterdam, The Netherlands

Abstract

Introduction: This study aims to provide insight into the prevalence of health problems and the frequency of general practitioner (GP) contacts in cohabiting partners of persons with dementia, during the year prior to the dementia diagnosis and up to 3 years after the diagnosis.

Methods: Partners of persons with dementia and a matched control group of partners of persons without dementia were identified in the routinely recorded electronic health records of 451 Dutch general practices in 2008–2015. These data were used to examine the prevalence of the partners' health problems. Differences between these partners and comparison partners in the prevalence of 16 groups of health problems (diagnostic chapters) and in the frequency of GP contacts were examined using generalized estimating equation models.

Results: 1,711 partners of persons with dementia and 6,201 comparison partners were included in the analyses. Social problems, more specifically problems related to the illness and/or the loss of the partner, were significantly more prevalent in partners than in comparison partners across the years (p < 0.01), as were musculoskeletal problems (p < 0.01). Respiratory and psychological problems increased over time in partners and remained stable in comparison partners. Across the years, partners contacted their GP more often than comparison partners (p < 0.01).

Discussion/Conclusion: Having a cohabiting partner with dementia has consequences for caregiver's physical and psychosocial health. The specific health problems found in

this study and the increase in GP contacts might be relevant indicators of overburdening in partners of persons with dementia.

Introduction

The majority of people with dementia live at home with support from their family members. If a partner is present, he or she is usually the person who fulfills the role of primary informal caregiver [1]. Family caregiving plays an increasingly vital role in care for people with dementia in European countries like the Netherlands, since policies encourage people to call on their own social network in the first place, supported by home and community-based services, in order to delay institutionalization [2, 3].

Providing family care can be a serious burden for caregivers and can negatively affect their psychological and physical health, especially among informal caregivers of persons with dementia [1, 4, 5]. For instance, caregivers of people with dementia show higher rates of depression, anxiety, sleeping disorders, and physical morbidity, including cardiovascular disease and lower immunity than noncaregivers, for example [6–9]. Furthermore, studies indicate that health-care use is higher among family caregivers of persons with dementia compared to noncaregivers [6, 10].

The health of family caregivers is one of the most important predictors of institutionalization of the person with dementia [11]. A majority of persons with dementia and their family caregivers prefer care at home [12] and institutionalized care increases health-care expenses [13]. It is therefore important to offer timely support to avoid deterioration of health in family caregivers and to enable them to maintain the care for their partner, relative, or friend with dementia as long as possible. Currently, there is limited insight into the occurrence of health problems and changes in health-care utilization in different stages of the care trajectory, while information about this is essential in order to offer timely support to family caregivers.

Furthermore, studies of health problems in family caregivers have mainly focused on psychological health outcomes as opposed to physical health outcomes and have used relatively small and selective study samples without a comparison group. There is a lack of evidence from large, representative population-based studies regarding the most prevalent psychosocial and physical health problems of partners caring for a person with dementia, and including a matching comparison group [14].

The aim of the current study is to provide insight into the prevalence of a wide range of psychosocial and physical health problems in cohabiting partners of persons with dementia that occur during the dementia care trajectory. In addition, this study aims to provide information on the frequency of contacts with the general practitioner (GP) during the dementia care trajectory. The research questions for this study are:

1. Which health problems are most prevalent among partners of people with dementia in the year prior to the dementia diagnosis and in the 3 years after the dementia diagnosis and to what extent do these differ from health problems in comparable partners of persons without dementia? Does the prevalence of these health problems change over time?
2. How often do partners of people with dementia contact their GP in the year prior to the diagnosis of dementia and in the 3 years after the diagnosis, does this frequency differ from that in comparable partners, and does it change over time?

Based on the previous systematic reviews (e.g., [6, 10]), we expected:
*   Psychological health problems, including, for example, depression, anxiety, and sleeping disorders, to be more prevalent in partners of people with dementia than in the comparison partners (H1);
*   Cardiovascular problems and immunity problems to be more prevalent in partners of people with dementia than in the comparison partners (H2);

_____

- The GP contact rate to be higher than for the comparison partners (H3).

Materials and Methods

Data from national administrative databases were linked with electronic health record (EHR) data from GPs. The data covered the year before and the 3 years following the dementia diagnosis. This time frame was chosen since Dutch data on dementia care trajectories have revealed that institutionalization in a long-term care facility often takes place approximately 3.5 years after the diagnosis is recorded in general practice [15].

Data Sources

EHR Data from GPs

Routinely recorded EHR data of GPs participating in the Nivel Primary Care Database (Nivel PCD) were used to retrieve data on psychosocial and physical health problems (https://www.nivel.nl/en/nivel-primary-care-database). The Nivel PCD collects pseudonymized EHR data on approximately 1.7 million individuals (10% of the Dutch population), which are routinely recorded by a nationally representative network of GP practices (451 for the current study), spread throughout the Netherlands [16]. This includes data on diagnoses, prescriptions, number of consultations, and referrals of all the patients who are registered with the participating GP practices. Diagnoses made by a specialist from a hospital or a memory clinic are also recorded by GPs. International Classification of Primary Care (ICPC-1) coding is used to code contact diagnoses [17] and grouped into disease episodes [18]. GPs receive support in coding and feedback on the quality of recording [19, 20]. In the Netherlands, the GP acts as the "gatekeeper" to specialist care and is therefore usually the first health-care provider people contact in the case of health problems. Virtually all Dutch residents are registered with a general practice.

Administrative Data

Data on sociodemographic characteristics, the date of death, and the date of institutionalization were derived from administrative data sources made available for research by Statistics Netherlands (Centraal Bureau voor de Statistiek, CBS). Statistics Netherlands is the governmental institution that is responsible for the processing of statistical population data in the Netherlands. Sociodemographic characteristics and date of death originated from the Municipal Personal Records Database, covering all persons residing in the Netherlands. The date of permanent institutionalization was derived from administrative data for the Dutch national long-term care insurance scheme covering all institutionalizations (nursing, residential, or psychiatric homes) of all Dutch adults.

Study Population

Partners of Persons with Dementia

Partners of persons born in 1965 or before with a recorded dementia diagnosis (ICPC code: P70) between 2008 and 2015 were identified in the EHR data. Partners were included based on the following criteria: living at the same household address, living together with ≤5 persons at the same address, and having an age difference with the person with dementia ≤20 years. Living together with more than 5 persons at the same address could imply that the person lives in a residential care home and these cases were therefore excluded (n = 56). If the age difference is <20 years, it is more likely that the person in question is not the partner of the person with dementia, therefore these cases were excluded (n = 18). Households with more than 1 person with dementia were also excluded.

_____

Comparison Group

For every person with a recorded dementia diagnosis, an independent researcher identified, if available, a maximum of 4 comparison persons without a recorded dementia diagnosis from the same general practice, in the same age category (5-year intervals), of the same sex, and living with a partner. A maximum of 4 comparison persons was identified because a large comparison group increases the reliability of the findings. The partners of these comparison persons were included as comparison partners in the current study. Neither the comparison persons nor their partners were diagnosed with dementia during the study period. Both were usually registered with the same general practice.

Outcomes

Psychosocial and Physical Health Problems

The prevalence of psychosocial and physical health problems was operationalized as a morbidity or symptom as recorded in the partner's or comparison partner's EHR during a specific year. GPs can use a total of 685 different ICPC codes to record diagnoses that are clustered into 17 ICPC chapters, reflecting different systems of the human body. In this study, we used 16 ICPC chapters (excluding the chapter about pregnancy) as health indicators. If significant differences ($p \leq 0.01$) were found in the prevalence of specific ICPC chapters between the partners and comparison partners, further analyses were conducted to examine whether there were differences between the samples at the ICPC level within that specific chapter.

Frequency of GP Contacts

The frequency of GP contacts in each year was obtained from the EHRs. Contacts included medical consultations at the GP's practice, home visits, and telephone consultations.

Sociodemographics Characteristics

The following sociodemographic characteristics of the persons with dementia and their partners and of the comparison persons and comparison partners were described: age, gender, and migrant status. The migrant status was categorized as a Western background (Dutch or Western migration background) or as a non-Western migration background (Surinamese, Antillean, Aruban, Moroccan, Turkish, or other non-Western migration background).

Frailty

A frailty index was created for the persons with dementia and the comparison persons in order to obtain an impression of their health condition. The frailty index was created by screening the GPs' EHRs for 35 predefined relevant "health deficits" including ICPC codes of diseases and symptoms and one deficit "polypharmacy" [21]. The proportion of deficits present in an individual resulted in the Frailty Index score (range 0–1). In accordance with prior studies, people were classified into nonfrail (3 or fewer deficits; Frailty Index ≤0.08), pre-frail (4 to 8 deficits; 0.08 <index <0.25), and frail (9 or more deficits; index ≥0.25) [22–24].

Date of Death and Date of Institutionalization

The date of death and date of institutionalization of the persons with dementia and their partners and of the comparison persons and comparison partners were determined to describe the proportion of persons who moved to a long-term care facility or died during the study period.

_____

Data Linkage

The GP data were pseudonymized at the source (i.e., the GP practice) and linked to the administrative data at Statistics Netherlands after being securely transferred by a trusted third party [16]. Pseudonyms were based on the citizen service number or on a combination of date of birth, gender, and postal code. The pseudonymized data were made accessible to the researchers through a secured remote access facility provided by Statistics Netherlands under strict privacy conditions.

Statistical Analysis

Descriptive statistics were calculated to describe the sample characteristics. χ^2 and independent t tests were used to determine differences between sample characteristics. The prevalence of the 16 ICPC chapters and the frequency of GP contacts were calculated and described per year for both partners and comparison partners.

To examine whether the prevalence of health problems and the number of GP contacts differed significantly between the partners and comparison partners and to examine whether the prevalence of health problems increased or decreased over time, generalized estimating equation (GEE) models were fitted. GEE models take into account the correlation of different measures within subjects.

For each of the 16 ICPC chapters, a GEE model for binary response variables was fitted, with the measurement year (continuous ranging from 0 to 3), partner group (partner vs. comparison partner), and the interaction term measurement year*partner group as predictors.

If a significant difference ($p \leq 0.01$, because of multiple testing) was found between partners and comparison partners in the prevalence of ICPC chapters, GEE models were fitted for all specific health problems (specific ICPC codes) that fell within those overarching ICPC chapters. 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.

In addition, a GEE model for count response variables was fitted to estimate changes over time in the number of GP contacts. This model also had the measurement year, partner group, and measurement year*partner group as predictors.

All analyses were based on study subjects who were registered at a GP practice for at least one entire follow-up year. All analyses were conducted in SPSS version 15.

[Figure 1] [Table 1]

Results

Sample Characteristics

Figure 1 shows the inclusion of partners and comparison partners per year. A total of 1,711 partners and 6,201 comparison partners were included in the analyses. The mean number of follow-up years was 2.3 years in both groups (see Table 1). The partners as well as the persons with dementia were slightly but significantly older than the comparison partners and the comparison persons without dementia (75.4 vs. 74.3 years and 78.1 vs. 76.8 years, respectively, see Table 1). The partners had a mean age of 75 and the comparison partners a mean age of 74. In both groups, almost all of the partners were of Western origin (97 and 98%, respectively). A significantly higher proportion of the partners of the persons with dementia cared for a frail person than the comparison partners and a significantly higher proportion of the persons with dementia moved to a long-term care facility (21 vs. 2%) or died (16 vs. 10%) during the study period than the comparison persons.

[Figure 2]

Health Problems in Partners and Comparison Partners in the Year before and the Three Years after Diagnosis

Figures 2 and 3 show that musculoskeletal problems were most prevalent across the years in both the partner (41–46%) and the comparison partner group (38–40%). Differences between partners and comparison partners were found for the following health problems:

- Social problems were more prevalent in partners than in comparison partners (OR = 4.98 [95% CI = 4.27–5.80]; p < 0.01). The prevalence of social problems increased over time in both the partner and comparison partner group (OR = 1.20 [95% CI = 1.12–1.28]; p < 0.01).
- Within the "social problems" chapter, we found "problems with the illness of the partner" to be more prevalent in partners than in comparison partners (OR = 10.55 [95% CI = 8.15–13.67]; p < 0.01). The prevalence increased over time in both the partner and the comparison partner group (OR = 1.26 [95% CI = 1.11–1.44]; p < 0.01). Furthermore, within this chapter "problems with the loss/death of the partner" increased over time in the partner group, but remained stable over time in the comparison partner group (OR = 1.47 [95% CI = 1.28–1.69]; p < 0.01).
- Problems related to the musculoskeletal system were more prevalent in partners than in comparison partners (OR = 1.14 [95% CI = 1.03–1.27]; p = 0.01). The prevalence remained stable over time in both groups.
- Respiratory problems increased over time in the partner group (OR = 1.14 [95% CI = 1.06–1.23]; p < 0.01), but remained stable over time in the comparison partner group.
- Psychological problems increased over time in the partner group (OR = 1.18 [95% CI = 1.07–1.31]; p < 0.01), but remained stable over time in the comparison partner group.
- Within the "psychological problem" chapter, "sleep disturbance" increased over time in the partner group (OR = 1.37 [95% CI = 1.16–1.63]; p < 0.01), but remained stable over time in the comparison partner group.

Furthermore, in both partners and comparison partners, a significant increase over the years was found in the prevalence of general and unspecified health problems (OR = 1.06 [95% CI = 1.02–1.10]; p < 0.01) and in the prevalence of urological problems (OR = 1.06 [95% CI = 1.02–1.10]; p < 0.01).

GP contacts in partners and comparison partners in the year before and the 3 years after diagnosis.

It was found that partners had more GP contacts than comparison partners across the years (B = 0.12 (95% CI = 0.06–0.18); p < 0.01). Partners had 9–10 contacts per year throughout the study period, whereas comparison partners had 7–8 contacts per year; see Figures 4 and 5. In addition, the number of GP contacts increased over time in the partner group but not in the comparison partner group (B = 0.05 [95% CI = 0.01–0.08]; p < 0.01).

Discussion

Reflection on Main Findings

This study provided insight into the most prevalent psychosocial and physical health problems among persons taking care of their partner with dementia during the year before the dementia diagnosis was recorded in the GP's electronic medical records and the 3 years after the diagnosis. These health problems were compared to the health problems of a matched comparison group.

We found musculoskeletal problems to be the most prevalent type of health problem across all years in both partners and comparison partners, which is in line with international research that suggests that musculoskeletal problems are one of the most prevalent health problems in older people [25]. Musculoskeletal problems were more prevalent overall in partners than in comparison

_____

partners, which could be related to the provision of family care, but might also be related to differences in, for instance, the socioeconomic position of the partners and comparison partners.

We expected that psychological health problems, including depression, anxiety, and sleeping disorders, would be more prevalent in partners than in comparison partners after the diagnosis of dementia (H1). This hypothesis was partly confirmed, as an increase in the prevalence of psychological problems, and specifically sleeping problems, over time was found in the partner group and not in the comparison partner group.

[Figure 3][Figure 4][Figure 5]

Besides sleeping problems, no other specific psychological health problems, such as depression, were significantly more prevalent in partners than in comparison partners during the year before and the 3 years after the diagnosis. In contrast, a comparable Dutch study showed that spouses of persons with dementia were 4 times more likely to be diagnosed with depression than spouses of persons without dementia [7]. In this study, a cohort of spouses was followed for 6 years, but not specifically immediately after the diagnosis. It could be that depression in spouses only manifests several years after the diagnosis, and our follow-up time was too short to detect this. Another explanation for not finding a higher prevalence of psychological problems might be that GPs are more likely to label depressive feelings or other psychological problems in partners of persons with dementia as "problems with the illness of the partner," which we found to be more prevalent in partners than in comparison partners.

We also expected that cardiovascular problems and problems related to immunity would be more prevalent in partners than in comparison partners after the diagnosis of dementia (H2), as described in the study of Brodaty and colleagues [6]. No significant differences were found with respect to cardiovascular problems between partners and comparison partners, but we did find an increase of respiratory problems in partners over the years that was not found in the comparison partners. The increase in respiratory problems may be related to immunity problems [6] although this could not be investigated in the current study.

Third, we expected that partners of persons with dementia would visit their GP more often after the diagnosis than comparison partners (H3). In accordance with previous research [6, 10], it was found that during the entire study period partners visited their GP more often than comparison partners, with a peak in the third year after the diagnosis.

Since the formal diagnosis of dementia is often given after the disease has been manifest for a while, it is likely that partners already struggle in dealing with dementia before this formal diagnosis and therefore may visit their GP more often. This possible explanation is supported by the finding that during the year before the diagnosis, partners visited their GP more frequently for problems with the illness of the person they were living with than comparison partners.

The increase in the number of GP contacts over the years in partners, which was not seen in the comparison partners, seems to confirm that caring for a partner with dementia becomes increasingly demanding over the course of time and may affect the health of the informal caregiver. This assumption is also supported by the finding that, compared to earlier years, the third year after the diagnosis shows more health problems that are more prevalent in partners than in comparison partners.

In addition, we found that social problems, reflecting problems with the disease and loss or death of the person with dementia, were 3 to 5 times more prevalent in partners than in comparison partners in the year before the dementia diagnosis and in the 3 years after the diagnosis. The prevalence of social problems was lowest before the diagnosis and showed a peak during the first year after the diagnosis, which gradually decreased in the following years. This pattern could be due to the fact that after the diagnosis, partners face many uncertainties and contact their GP in need of

_____

_____

support. As the disease progresses over the years, it could be that informal caregivers are somewhat more prepared for the future or are receiving support by then.

Nevertheless, given the high prevalence of problems with the disease or loss of the person with dementia in partners compared to comparison partners over the years, partners seem to be in need of advice or support in relation to the condition of their partner. Earlier survey research already highlighted this need among family caregivers at all stages of dementia [26].

Strengths and Limitations

An important strength of this study is that a large group of partners of persons with dementia was followed during several years of the care trajectory and a wide range of psychosocial and health problems were examined using routine registration data. In addition, we were able to include a large group of comparison partners with a long follow-up period as well.

Because of the gatekeeping health-care system in the Netherlands in combination with the comprehensive use of EHRs with guidelines for proper EHR keeping [19] and the possibility of record linkage with pseudonymized data, it was possible to use existing data to identify and follow-up partners of people with dementia without increasing the administrative burden for health professionals.

A limitation of this study is that dementia is likely to be under-recorded in Dutch primary care. There seems to be a reluctance to record dementia in EHRs if it is not yet officially confirmed by a medical specialist. This means that it is possible that some of the partners and comparison partners as well as the partners of the comparison partners might have had dementia but were not yet diagnosed as such.

A second limitation is that in theory a few cohabiting children might have been included in the partner group. However, since cohabiting partners were selected based on the criterion that the age difference with the person with dementia should be ≤20 years and teenage pregnancies are rare in The Netherlands, this number would the negligibly low and would therefore not have affected the outcomes of our study.

Conclusion

The findings of the current study imply that having a cohabiting partner with dementia has consequences for the caregiver's physical and psychosocial health. This is reflected by a higher prevalence of musculoskeletal problems, respiratory problems, psychological problems, and especially social problems as well as an increase in GP contacts, over the course of multiple years prior to and following the diagnosis of dementia. In practice, this means that the increase in the number of people with dementia will be accompanied by an increased appeal to GPs by partners of people with dementia. Given the finding that partners often visit the GP for problems with the disease of the person with dementia, timely referral to for instance a case manager dementia for support is important. Support for partners seems needed throughout the disease trajectory, starting in the first year after or even before the diagnosis of their relative. This could contribute to the prevention of overburdening in partners, of which the specific health problems and the increase in GP contacts as found in this study might be relevant indicators.

Statement of 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 Nivel PCD, under number NZR-00315.063. Patients were informed by their GP about the use of their pseudonymized health data and could object. Data were processed in accordance with national and EU regulations and guidelines. The use of EHRs for research purposes is allowed under certain conditions. When these conditions are fulfilled, neither obtaining informed consent from patients nor approval by a Medical Ethics Committee is obligatory

_____

for this type of observational studies containing no directly identifiable data (art. 24 GDPR Implementation Act jo art. 9.2 sub j GDPR).

Conflict of Interest Statement

The authors have no conflicts of interest to declare.

Funding Sources

Author Contributions

K. Joling, H. van Hout, A. Francke, R. Verheij, and I. van der Heide planned the study. I. van der Heide performed the statistical analyses and wrote the manuscript. K. Joling, H. van Hout, A. Francke, and M. Heins supervised the data analysis. K. Joling, H. van Hout, A. Francke, R. Verheij, and M. Heins contributed to revising the manuscript.

References

1 Schulz R, Martire LM. Family caregiving of persons with dementia: prevalence, health effects, and support strategies. Am J Geriatr Psychiatry. 2004; 12: 240–9.
2 Gibson MJ, Gregory SR, Sheel MP. Long-term care in developed nations: a brief overview. Washington: The AARP Public Policy Institute; 2003.
3 Colombo F, Llena-Nozal A, Mercier J, Tjadens F. Help wanted? Providing and paying for long-term care. OECD health policy studies. Paris: OECD Publishing; 2011.
4 Bleijlevens MH, Stolt M, Stephan A, Zabalegui A, Saks K, Sutcliffe C, et al. Changes in caregiver burden and health-related quality of life of informal caregivers of older people with Dementia: evidence from the European RightTimePlaceCare prospective cohort study. J Adv Nurs. 2015; 71: 1378–91.
5 Pinquart M, Sörensen S. Correlates of physical health of family caregivers: a meta-analysis. J Gerontol B Psychol Sci Soc Sci. 2007; 62: 126–37.
6 Brodaty H, Donkin M. Family caregivers of people with dementia. Dialogues Clin Neurosci. 2009; 11: 217–28.
7 Joling KJ, van Hout HP, Schellevis FG, van der Horst HE, Scheltens P, Knol D, et al. Incidence of depression and anxiety in the partners of patients with dementia: a naturalistic cohort study of recorded morbidity with a 6-year follow-up. Am J Geriatr Psychiatry. 2010; 18: 146–53.
8 Joling KJ, van Marwijk HW, Veldhuijzen AE, van der Horst HE, Scheltens P, Smit F, et al. The two-year incidence of depression and anxiety disorders in spousal caregivers of persons with dementia: who is at the greatest risk? Am J Geriatr Psychiatry. 2015; 23: 293–303.
9 Vitaliano PP, Zhang J, Scanlan JM. Is caregiving hazardous to one's physical health? A meta-analysis. Psychol Bull. 2003; 129: 946–72.
10 Bremer P, Cabrera E, Leino-Kilpi H, Lethin C, Saks K, Sutcliffe C, et al. Informal dementia care: consequences for caregivers' health and health care use in 8 European countries. Health Policy. 2015; 119: 1459–71.
11 Eska K, Graessel E, Donath C, Schwarzkopf L, Lauterberg J, Holle R. Predictors of institutionalization of dementia patients in mild and moderate stages: a 4-year prospective analysis. Dement Geriatr Cogn Dis Extra. 2013; 3: 426–45.
12 Tew CW, Tan LF, Luo N, Ng WY, Yap P. Why family caregivers choose to institutionalize a loved one with dementia: a Singapore perspective. Dement Geriatr Cogn Disord. 2010; 30: 509–16.

Heide, I. van der, Heins, M., Verheij, R., Hout, H.J.P. van, Francke, A., Joling, K. Prevalence of health problems and health-care use in partners of people with dementia: longitudinal analysis with routinely recorded health and administrative data. Gerontoloy: 2021

_____

13 Schwarzkopf L, Menn P, Kunz S, Holle R, Lauterberg J, Marx P, et al. Costs of care for dementia patients in community setting: an analysis for mild and moderate disease stage. Value Health. 2011; 14: 827–35.

14 Roth DL, Fredman L, Haley WE. Informal caregiving and its impact on health: a reappraisal from population-based studies. Gerontologist. 2015; 55: 309–19.

15 Joling KJ, van der Heide I, Verheij R, Francke A, van Hout HP. Infographic. Care trajectories of people with dementia: results of the BESIDE project [Zorgtrajecten van mensen met dementie in kaart: resultaten van het BESIDE project]. Utrecht: Nivel; 2019.

16 Kuchinke W, Ohmann C, Verheij RA, van Veen EB, Arvanitis TN, Taweel A, et al. A standardised graphic method for describing data privacy frameworks in primary care research using a flexible zone model. Int J Med Inform. 2014; 83: 941–57.

17 Lamberts H, Wood M. International classification of primary care (ICPC). Oxford: Oxford University Press; 1987.

18 Nielen MMJ, Spronk I, Davids R, Korevaar JC, Poos R, Hoeymans N, et al. Estimating morbidity rates based on routine electronic health records in primary care: observational study. JMIR Med Inform. 2019; 7: e11929.

19 Van der Bij S, Verheij RA. Pay for performance scheme 2013 led to improvement in HER data recording [Inzet variabiliseringsgelden 2013 leidt tot belangrijke verbetering EPD]. SynthesHIS. 2013; 4: 2.

20 Verheij RA, Curcin V, Delaney BC, McGilchrist MM. Possible sources of bias in primary care electronic health record data use and reuse. J Med Internet Res. 2018; 20: e185.

21 Drubbel I, de Wit NJ, Bleijenberg N, Eijkemans RJ, Schuurmans MJ, Numans ME. Prediction of adverse health outcomes in older people using a frailty index based on routine primary care data. J Gerontol A Biol Sci Med Sci. 2013; 68: 301–8.

22 Rockwood K, Andrew M, Mitnitski A. A comparison of two approaches to measuring frailty in elderly people. J Gerontol A Biol Sci Med Sci. 2007; 62: 738–43.

23 Rockwood K, Howlett SE, MacKnight C, Beattie BL, Bergman H, Hébert R, et al. Prevalence, attributes, and outcomes of fitness and frailty in community-dwelling older adults: report from the Canadian study of health and aging. J Gerontol A Biol Sci Med Sci. 2004; 59: 1310–7.

24 Song X, Mitnitski A, Rockwood K. Prevalence and 10-year outcomes of frailty in older adults In relation to deficit accumulation. J Am Geriatr Soc. 2010; 58: 681–7.

25 Fejer R, Ruhe A. What is the prevalence of musculoskeletal problems in the elderly population in developed countries? A systematic critical literature review. Chiropr Man Therap. 2012; 20: 31.

26 Zwaanswijk M, Peeters JM, van Beek AP, Meerveld JH, Francke AL. Informal caregivers of people with dementia: problems, needs and support in the initial stage and in subsequent stages of dementia: a questionnaire survey. Open Nurs J. 2013; 7: 6–13.

Tables and figures
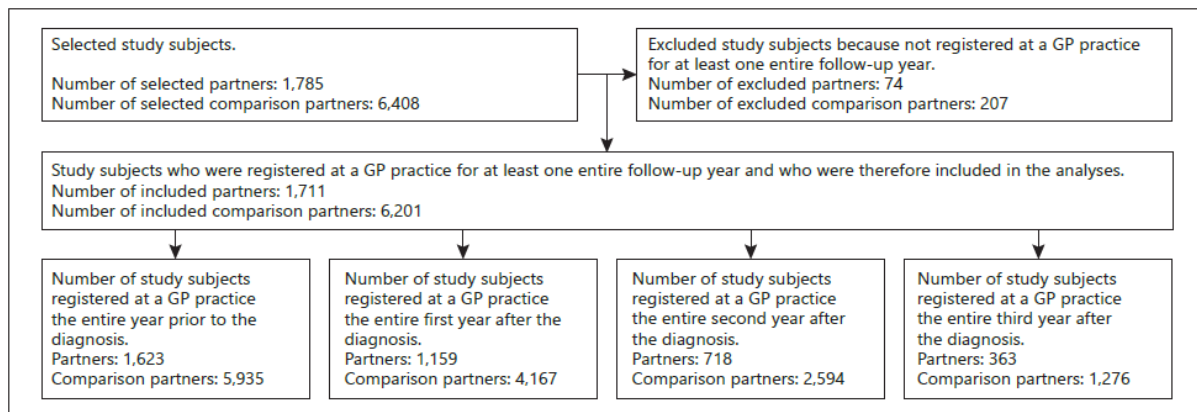
Figure 1.   Flowchart included study subjects.

Table 1. Characteristics of the included partners, comparison partners, persons with dementia, and comparison persons without dementia

	Partners	Comparison partners	Persons with dementia	Comparison persons without dementia
n	1,711	6,201	1,711	6,201
Female, %	59.1	59.1	41.6	41.0
Age at moment of dementia diagnosis[a], (mean ± SD); median	75.4 (8.4)*; 76.0	74.3 (8.0); 75.0	78.1 (7.80)*; 79.09	76.8 (7.3); 77.7
Age categories, %				
<65	10.7	11.7	6	6.7
65–74	31.8*	35.3	25.5*	28.4
75–84	43.7	44.5	49.9*	53.1
≥85	13.8*	8.4	18.6*	11.1
Migration background				
Western, %	97.3	97.6	97	97
Deceased during study period, %	6	5.1	16*	10
Follow-up in years, (mean ± SD)	2.3 (1.1)	2.3 (1.1)	–	–
Moved to long-term care facility during study period, %	–	–	21*	2
Frailty index, %				
Nonfrail (<0.09)	–	–	14.5*	37.6
Pre-frail (0.09–0.24)	–	–	70.9*	56.8
Frail (>0.24)	–	–	14.6*	5.0

* Significantly different from comparison partner/comparison person without dementia based on χ^2 or *t* test and $p < 0.05$. [a] For (comparison) partners and comparison persons with dementia, the moment (date) of diagnosis in the person with dementia was used as reference date.

Figure 2. Prevalence of health problems in partners of persons with dementia in the year prior to and the 3 years after the diagnosis.
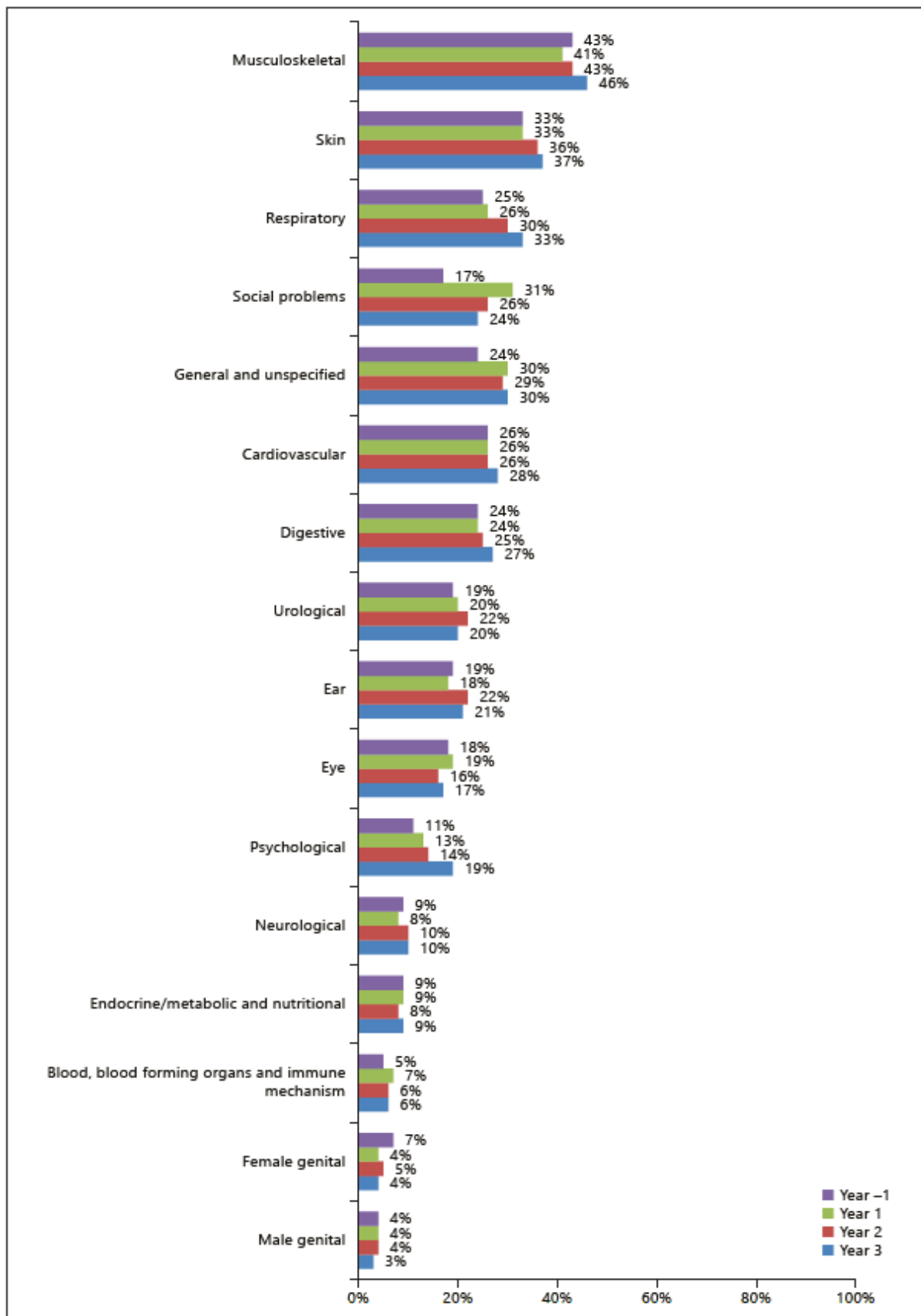
Figure 3. Prevalence of health problems in comparison partners in the year prior to and the 3 years after the diagnosis dementia in the person with whom the comparison couple was matched.
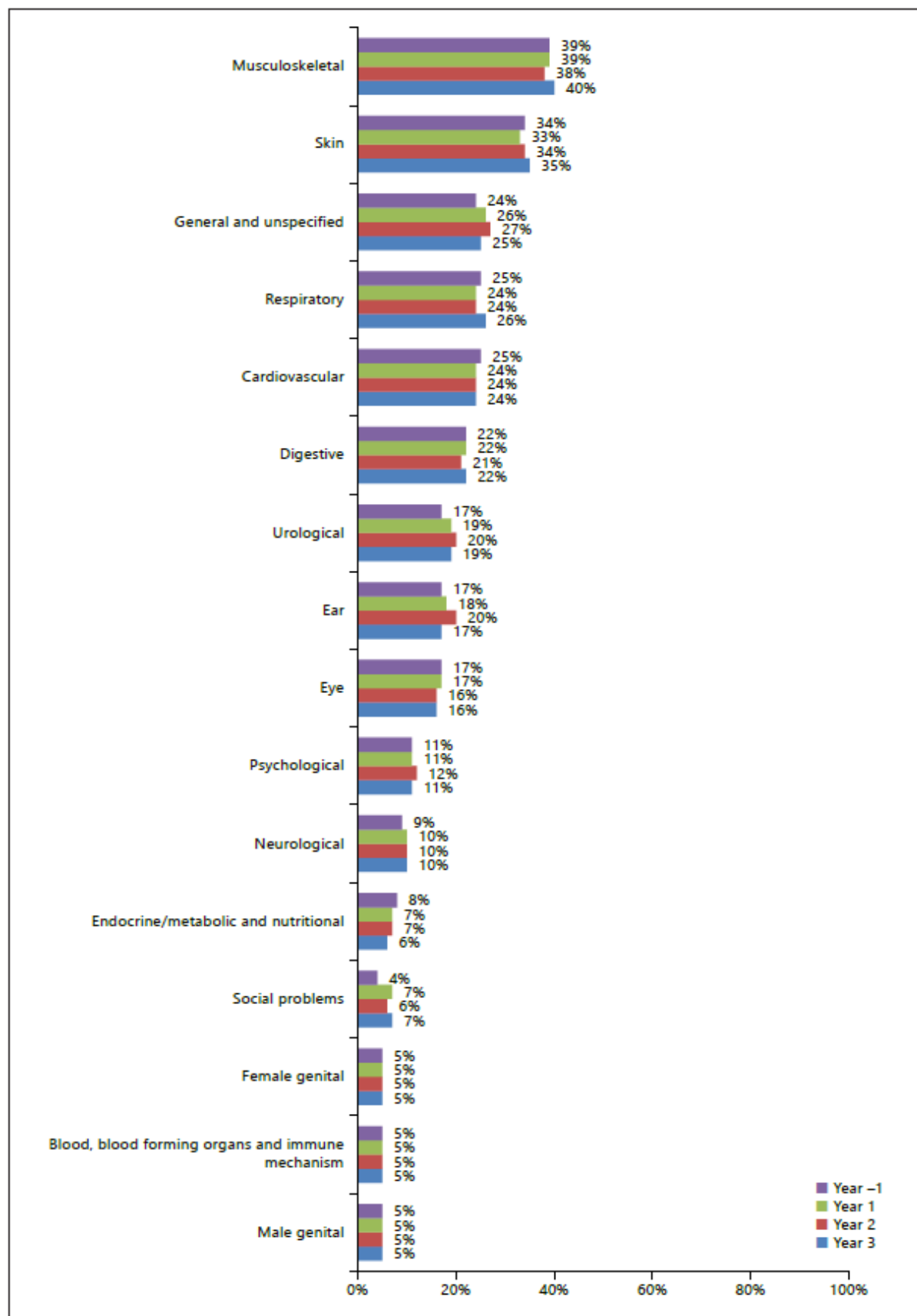
Figure 4. Mean number (95% CI) of GP contacts per year in partners of persons with dementia before and after the diagnosis dementia. GP, general practitioner.
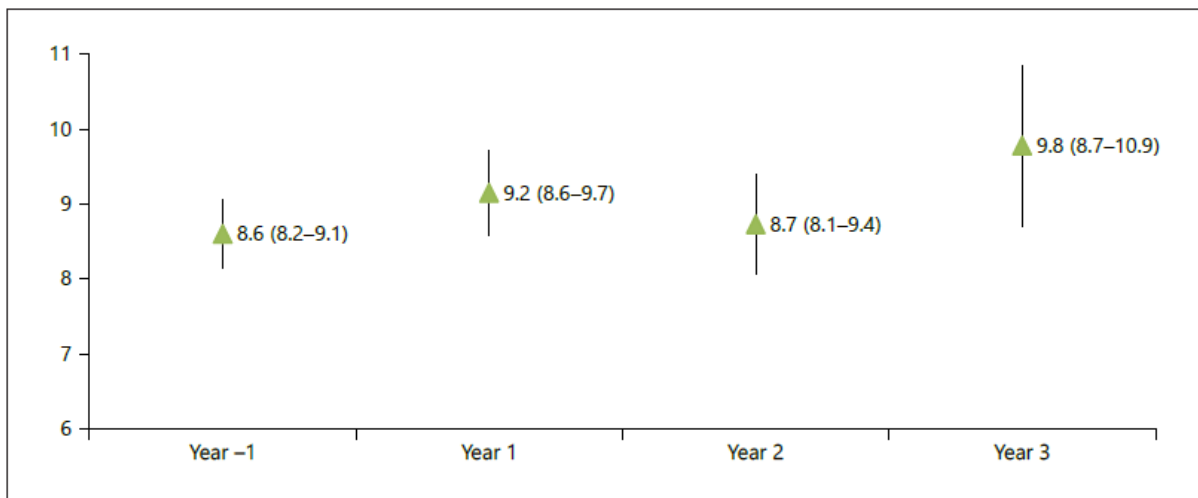

Figure 5. Mean number (95% CI) of GP contacts per year in comparison partners before and after the diagnosis dementia in the person with whom the comparison couple was matched. GP, general practitioner.