Informal caregivers - Germany’s largest nursing service

In recent decades, life expectancy within the population has increased significantly. Many older people spend a large part of these extra years in mostly good health (Robert Koch Institut 2008, Trachte et al. 2014, Doblhammer, Kreft 2011). Because of this demographic ageing however, the total number of older people with age and illness-related limitations is increasing. Of these, many are dependent on help or professional care be it temporarily or in the longer term. Permanent nursing and support of care dependent persons (in the following: long-term care) is therefore becoming an ever more important part of healthcare provision.

Need for long-term care may be understood as a temporary or permanent crisis of independent living as a result of a physical, mental or cognitive impairment. The voluntary support of those affected offered by informal caregivers (i.e. family, friends and neighbours) makes an important and positive contribution toward living together in partnership as well as to cohesion of the generations. A person’s need for long-term care can, for immediate family and friends, also bring with it health-related and mental stresses, as well as social risks as a result of financing support services or loss of earnings (Robert Koch Institut 2008, R+V, IfD Allensbach 2012, Schmidt, Schneekloth 2011).

Prior to the introduction of long-term care insurance in Germany in 1995, nursing and care of people with a long-term care requirement was not regulated as part of social security legislation. Alongside support from family and friends, those affected were able to fall back on services provided by social organisations and municipalities, partly funded through the Federal Social Assistance Act (Gellinger, Röber 2014). In view of the rising care requirement, 1995 saw the introduction of social long-term care insurance as the fifth pillar of the social security system in Germany with Volume 11 of the Social Security Code (SGB XI). Since then compulsory statutory and private insurance means that a far greater part of the risk associated with the need for long term care is secured via a legal right to care services (Bundesministerium für Arbeit und Sozialordnung 1997). A need for care and support is acknowledged according to whether there is a dependency on long-term care as defined in social legislation.

In this context, any person is considered to be entitled to benefits if due to a physical, mental or emotional illness or disability, they will require a substantial or increased level of assistance in carrying out normal and regularly occurring activities as part of everyday life in the longer term and for a period expected to last at least six months. (§14 para. 1, SGB XI). A need for long-term care in the context of social legislation is established by means of an individual assessment by the German Health Insurance Medical Service (MDK) and essentially falls into one of three level of care categories: substantial need of care (Care Level 1), severe need of
The legal and financial security of informal caregivers

From projections based on the GEDA 2012 study, it is possible to conclude that approximately 4 to 5 million informal caregivers, particularly close family members, are involved in looking after persons in need of long-term care living in their own homes. There is no direct state financial support for these caregivers. If the insured person decides to receive care allowance, this money should be used to cover and provide for household and care needs. The legislator makes the fundamental assumption here that care is provided by family and friends on a voluntary basis. The informal caregiver may however also receive some kind of financial recognition or expenses allowance from the person in need of long-term care.

In addition, informal caregivers are insured against accidents regardless of the length of time spent working as a caregiver. For informal caregivers providing personal or domestic help and long-term care at least 14 hours per week, the long-term care insurance will pay contributions toward statutory pension insurance in line with §44 SGB XI, as long as the carer is not employed more than 30 hours per week making them liable to pay social security contributions. The level of contributions is based on the number of care hours per week and the care level. In addition, support may be available for further vocational training in accordance with SGB III.

The First Act to Strengthen Long-Term Care which came into effect on January 1, 2015 is intended to improve support for informal caregivers. For example, there is more money available for short-term, daytime and night-time care, as well as for respite care, which will be required if the carer is unwell or has to take a break. Given the acute onset of a situation requiring care where care on the part of a close relative needs to be organised or ensured, it is possible to take a period of up to ten days off work. For this period off work it is possible that a “care support allowance” may be paid, limited to ten days. A legal right to leave to care for family was introduced in Germany on 1 January, 2015 with the “Act to Improve Compatibility between Family, Care and Work”. This therefore gives employees a right to partial leave of absence for up to 24 months if they are looking after a close relative requiring long-term care in the home environment.

To support informal caregivers, long-term care insurance for example, offers care courses in which carers can learn practical skills either in groups or individually at home. In addition to this, group training sessions offer the opportunity to exchange experiences with other carers. In the past, however, only a small portion of around 12% of informal caregivers have taken advantage of this offer (Schmidt, Schneekloth 2011). In addition to the care courses, informal caregivers also have had a legal right to care counselling via the care insurance funds since 2009. This offer subsequently found resonance among those affected and consequently represents an important further development in their support (Klie et al. 2011).
However, many carers are not completely alone in caring for their family and friends: In approximately one quarter of all cases of people needing long-term care being cared for at home, two relatives share the care and in a further quarter there are even three or more persons involved (Schmidt, Schneekloth 2011). In addition, study results show that if the caregivers are gainfully employed this is also to be seen as a resource in itself. Being in gainful employment makes it possible to cope better with the stressors resulting from being a carer because important social contacts can be maintained and a piece of temporal autonomy preserved within their own lives (Bundesministerium für Gesundheit 2012, Lehr 2010).

Mainly women provide informal care
Even if the percentage of male carers is gradually increasing (Schmidt, Schneekloth 2011), informal at home care is mainly provided by women, mostly by daughters, spouses, daughter-in-laws or mothers of the person needing long-term care. According to the results of the 2012 GEDA study, 6.9 % of adults regularly provide informal care for a person with a long-term need. Among women this percentage is significantly higher at 8.7 % than it is among men at 4.9 % (Fig. 1). Hence, almost two thirds of caregivers are women (64.9 %) and a good third are men (35.1 %).

With age the proportion of informal caregivers increases rapidly, especially among women. Proportionally, women then assume tasks within the scope of providing long term care for persons close to them significantly more frequently than men. In the 55 to 69-year-old age group the proportion of informal caregivers is at its highest level: 11.9 % of women and 6.0 % of men of this age support friends or family in need of long-term care. 2.6 % of adults provide occasional

Motives, stressors and resources
Whoever decides to care for a person close to them at home normally does so out of loving affinity, gratitude or due to a sense of obligation. These motives are often mixed with other reasons such as a lack of other care alternatives (GKV-Spitzenverband 2011). Sometimes the care situation has a gradual onset with smaller acts of support such as helping with shopping or household chores and develops step by step into all-round care. According to the results of the EUROFAMCARE study, in Germany the main reasons for the assumption of a carer’s role are emotional ties between the caregiver and the family member in need of long-term care (Döhner et al. 2007). One third of all informal caregivers feel obligated to assume the care.

The great majority is also prepared to continue providing care - even if this means more effort for them in the future. More than 90 % of carers have a good relationship with the person needing long-term care; they feel providing care services is worthwhile, feel valued in the role and the majority come to terms well with the care situation (Döhner et al. 2007).

However, the provision of care services by family and friends is also associated with various stressors. Key aspects are the feeling of having to be available around the clock and the high amount of time required to provide care. For many family members or friends, striking a balance between their own job, partnership, looking after children and their own leisure time whilst at the same time overcoming the bureaucratic tasks associated with care represents a major challenge. This impacts on physical and mental health, the social network and working life (Bundesministerium für Gesundheit 2012). The majority of informal caregivers have no previous care experience.
care, 2.0% up to two hours per day and 2.1% at least two hours per day for a person within or outside of their own household. The difference between the genders becomes particularly clear among those carers providing care for two hours or more daily: 3.2% of women but only 1.0% of men (Fig. 2). Accordingly, the share of women among carers with this care workload also increases: Among those who provide occasional care the share of women is 58.2%; among those providing care for at least two hours per day, over three quarters are women (77.2%).

**Socio-demographic characteristics**

An analysis of social characteristics of informal caregivers and non-caregiving persons reveals that notable differences can be found mainly between those people who do not provide care and those who provide care for their family and friends for two hours per day or longer (carers with high care workloads). This is also the group of people that has a right to pension insurance because of their care duties.

The average age of female caregivers with high care workloads is 53.4 years and that of corresponding men is 50.6 years both therefore being a good two years above the average age of non-carers. In comparison to non-carers those who provide more than two hours of informal care per day make up a lower share in the 18 to 29-year-old age group and a greater share in the 65 and over age group (Tab. 1).

Significant differences can also be seen with regard to educational status: Informal caregivers with high care workloads more frequently belong to lower and less frequently to more highly educated groups than non-carers. Among women these differences remain when age differences are taken into account.

On examining labour market participation, it becomes apparent that those men and women providing at least two hours of informal care are significantly less often employed than non-carers. These differences only remain with regard to men once adjusted for age.

Social support is among those psychosocial resources that have a fundamental influence on health. It can have a direct effect on mental well-being, reduce stress and alleviate the effects of unfavourable living conditions (Robert Koch Institut 2014, Robert Koch Institut 2012).

**Relationship between informal caregivers and care-dependent persons**

Almost nine out of ten informal caregivers surveyed provide care for a close family member in need of long-term care within or outside of their own household. Approximately one in ten carers is involved in the care of friends, acquaintances or neighbours. The great majority of informal caregivers therefore look after close family members and life partners. There is barely any distinction to be made between men and women in this regard.

The more time-consuming the care of family and friends becomes, the more often it takes place within the carer’s own home. Approximately three quarters (74.1%) of carers providing care for at least two hours per day look after members of their own household. People who only occasionally provide informal care mainly look after friends or family outside of their own households (66.0%). Only among those who occasionally provide care does the care of friends and acquaintances account for a significant share at 17.9%. In contrast, given high care workloads, this is of secondary importance (2.2%) (Fig. 3).
However, according to GEDA 2012, informal caregivers providing a high level of care show only low levels of social support significantly more often than non-carers. Even the percentages of people who have medium level social support feature lower among carers than those who do not provide care. In women this association persists after age correction.

State of Health

As part of the scientific debate many health-related and mental stressors for informal caregivers are the subject of discussion (Bundesministerium für Gesundheit 2012, Kummer et al. 2010). According to this, factors such as cognitive and behaviour-related problems of the person requiring long-term care, the duration of the carer role, old age or low levels of social support are closely associated with poorer physical health of informal caregivers (Pinquart, Sörensen 2007). Many studies also confirm that informal caregivers more often report reduced well-being, stress and mental disorders such as depression and anxiety disorders than non-carers (Butterworth et al. 2010).

Population based comparisons regarding the state of health of informal caregivers and non-caregivers are now possible using the GEDA 2012 data. Because health-related differences occur above all between carers providing 2 hours of care or more per day and non-carers, we shall focus in the following on informal caregivers with high care workloads. The following core indicators were used in order to describe the state of health: General state of health depicts the personal and social dimensions of one's own health and well-being. It is significant for the future use of health services and the occurrence of chronic diseases. The question “How is your health in general?” was used to survey general state of health (De Bruin et al. 1996). For the analyses the response categories “fair”, “bad” and “very bad” were summarised as “not good”.

The indicator for health limitations indicates to what extent the person interviewed is limited in the long-term in carrying out everyday activities for health reasons. In this case, the response categories “strongly limited” and “limited but not strongly” were summarised to “limited” (Jagger et al. 2008).

Back pain is very widespread among the population considerably restricting health-related quality of life and is of major significance with regard to the health economy. Debated risk factors for its occurrence are work-related psycho-social conditions such as low level job satisfaction, social conflicts and lack of recognition (Robert Koch Institut 2012). Depicted here is the prevalence of back pain lasting at least three months and occurring on an almost daily basis.

The number of days on which the person interviewed was unable to go about their everyday activities during the previous four weeks due to health restrictions is considered

### Table 1

<table>
<thead>
<tr>
<th>Age, educational and occupational structure and social support in informal caregivers with high care workloads and non-carers</th>
<th>Caregiving 2 hours daily and more</th>
<th>Non – caregiving</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Women</td>
<td>Men</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18–29 years</td>
<td>5.1 (2.6–10.0)</td>
<td>3.5 (0.9–13.2)</td>
</tr>
<tr>
<td>30–44 years</td>
<td>24.4 (16.4–34.7)</td>
<td>15.4 (8.4–26.4)</td>
</tr>
<tr>
<td>45–64 years</td>
<td>35.6 (27.7–44.4)</td>
<td>35.7 (24.8–48.4)</td>
</tr>
<tr>
<td>&gt;= 65 years</td>
<td>34.9 (26.5–44.3)</td>
<td>45.5 (32.6–58.8)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lower education group</td>
<td>45.2 (35.9–54.9)</td>
<td>46.7 (33.8–60.1)</td>
</tr>
<tr>
<td>Middle education group</td>
<td>47.8 (38.6–57.1)</td>
<td>34.6 (23.8–47.3)</td>
</tr>
<tr>
<td>Upper education group</td>
<td>7.0 (4.3–11.2)</td>
<td>18.6 (12.2–27.5)</td>
</tr>
<tr>
<td><strong>Currently employed</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>61.2 (51.7–69.9)</td>
<td>70.8 (58.9–80.4)</td>
</tr>
<tr>
<td>Yes</td>
<td>38.8 (30.1–48.3)</td>
<td>29.2 (19.6–41.2)</td>
</tr>
<tr>
<td><strong>If yes, degree of employment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full-time</td>
<td>46.5 (32.1–61.6)</td>
<td>76.0 (56.0–88.7)</td>
</tr>
<tr>
<td>Part-time</td>
<td>45.4 (31.2–60.5)</td>
<td>11.4 (3.7–30.3)</td>
</tr>
<tr>
<td>Casual / irregular</td>
<td>8.0 (3.5–17.3)</td>
<td>12.6 (4.4–31.4)</td>
</tr>
<tr>
<td><strong>Social support</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>36.1 (27.0–46.4)</td>
<td>37.7 (25.0–52.2)</td>
</tr>
<tr>
<td>Middle</td>
<td>38.3 (29.6–47.8)</td>
<td>37.9 (26.4–50.9)</td>
</tr>
<tr>
<td>High</td>
<td>25.6 (18.7–33.8)</td>
<td>24.5 (15.3–37.1)</td>
</tr>
</tbody>
</table>
an indicator for health-related quality of life. A distinction is made here between physical and mental health. In the following, those persons who were restricted in going about their everyday activities for at least 14 days within the previous four weeks due to their mental health are deemed to be severely mentally stressed (Centres for Disease Control and Prevention 2000).

Informal caregivers with high care workloads more frequently describe their general state of health as being "not good" than those in the comparison group. Higher percentages of them also report health limitations and mental stressors than non-carers. Among caregiving women, the percentage with back pain is also elevated compared to non-carers (Fig. 4).

Informal caregivers with high care workloads and non-carers differ greatly in relation to characteristics such as age, education, employment and social support (see above). Logistic regressions were calculated in order to check whether significant differences in state of health still exist between carers and non-carers even when these characteristics are controlled. With the exception of back pain, it can be seen that for women providing two hours or more care per day, the chances of health limitations, a bad general state of health or severe mental stress are still significantly increased even if the social discrepancies between the two groups is statistically controlled. This relationship between informal caregiving and state of health on the other hand does not prevail in men following statistical control of social discrepancies (Fig. 5).

Health behaviour
Poor diet, lack of exercise, obesity, smoking and hazardous alcohol consumption are among the most important factors influencing non-communicable chronic diseases. According to estimates by the WHO, 80% of cardiovascular disease and stroke, 80% of the cases of diabetes mellitus type 2 and 40% of cancer cases could be avoided given healthy diet, sufficient physical exercise and abstinence from the consumption of tobacco (WHO 2009, WHO 2005). Participating in sport also contributes toward avoiding a multitude of chronic diseases (Lee et al. 2012). In addition, the use of prevention services also helps to maintain good health. In this way, dental checks have a beneficial impact on oral and dental health and health-related quality of life (Micheelis, Schiffler 2006).

Therefore, analyses were conducted regarding to what extent informal caregivers with high care workloads differ from non-carers in their health behaviour. Any hazardous alcohol consumption was recorded via the three-question Alcohol Use Disorder Identification Test - Consumption (AUDIT-C) (Bush et al. 1998). People who stated that they had not participated in sport in the three months prior to the survey (hereinafter "no sport") are differentiated from those who occasionally or regularly partake in sport (Robert Koch Institut 2014). Those who smoke daily or occasionally (hereinafter "smokers") are distinguished from non-smokers (Robert Koch Institut 2014). Dental check ups in the last 12 months were used as an example for preventive health behaviour (Robert Koch Institut 2014).
Statistical differences in the health behaviour of informal caregivers and non-carers can be seen above all among women: Female carers with high care workloads smoke more often and do less sport than female non-carers. In contrast they tend to less frequently indulge in hazardous alcohol consumption. They also attend dental checks less frequently than female non-carers. As far as men are concerned, statistically significant differences are only to be found with regard to participation in sport: men who provide at least two hours of informal care daily do less sport than male non-carers. In contrast, with regard to smoking and hazardous alcohol consumption the differences between male caregivers and non-caregivers are not significant (Fig. 6).

Logistic regressions were calculated in order to check whether significant differences exist in the state of health between caregivers and non-caregivers whilst controlling for the characteristics of age, education, employment and social support. Here the differences highlighted only proved to be stable among women (Fig. 7). Even after social discrepancies are statistically controlled, the probability is significantly higher among female informal caregivers with high workloads compared to non-carers that they will not do sport, they will not go to dental check-ups and that they will smoke. Compared to female non-carers there is less risk that they will indulge in hazardous alcohol consumption. In men, after social factors are controlled, there are no discrepancies in health behaviour between male carers and non-carers.

**Discussion**

According to the results of GEDA 2012, 8.7% of women and 4.9% of men regularly provide informal care for a person in long-term need of care. After extrapolation this therefore means there are approximately 4.7 million informal caregivers in Germany. According to information contained in care statistics they provide care for 1.18 million people at home who are in need of care as per the Long-Term Care Insurance Act. It should be borne in mind that generally speaking several people are involved in the care of any one friend or relative; only 30% of persons in need of long-term care are cared for exclusively by one person (Schmidt, Schneekloth 2011).

Two thirds of carers are women, a good third are men. Since it is not possible using the GEDA data to differentiate between the main and supplementary carers, these details appear plausible in the light of previous findings (Schmidt, Schneekloth 2011). In GEDA 2012 the percentage of women among those providing more than two hours of care daily amounts to more than 75%. In the Sixth German Government Report on the Elderly (6. Altenbericht) the statement is to be found that 90% of carers in the context of Section 14 of Volume XI of the Social Security Code (SGB XI) - i. e. providing at least 14 hours per week care - are women (Bundesministerium für Familie Senioren Frauen und Jugend 2010). Here the groups are also not directly comparable since the question was not asked in the GEDA survey whether the informal caregivers are insured in accordance with Section 14 of SGB XI.

However, there is a consistent tendency that with increasing care workload, the proportion of women involved in caring for a relative increases too. With regard to employment status of the carer there is a good degree of conformity with earlier findings (Schmidt, Schneekloth 2011).
The health behaviour of female carers exhibits high risk levels than that of non-carers with the exception of lower alcohol consumption. This result confirms the findings of several studies on the impact of several social roles on alcohol consumption - such as partnerships, parenting and occupations. According to these, women like men who assume several social roles are at relatively low risk of exhibiting hazardous alcohol consumption levels (Kuntsche et al. 2009).

Even though caring for close family and friends also has positive aspects and is empowering with many carers feeling able to cope well with the stresses (Techniker Krankenkasse 2014), the health-related and psychological burdens resulting from the role of carer are not to be underestimated - especially when caring for dementia sufferers. Therefore, social support in the carer’s environment and other supportive services are especially important. The mental stress and drain on time due to being an informal caregiver may lead to a reduction in social contacts and all the way to social isolation (Kummer, et al. 2010). Social support can lessen the impact of stressors, make overcoming care tasks easier and promote behaviour conducive to health (Pinquart, Sörensen 2007). The GEDA 2012 data does however confirm that informal caregivers have to make do with less social support than non-carers.

Although Germany has a well-developed service structure of professional support, many of these services do not actually reach the informal caregivers. Carers are unaware of many of these services or they do not make use of them (Techniker Krankenkasse 2014). In part the service structure is also perceived to be confusing and bureaucratic. Another decisive factor is that the services take account of the carer’s wishes and living environment and that the carers can generally access them (Bundesministerium für Gesundheit 2012). Other findings indicate that informal caregivers frequently overestimate their resources and skills and therefore feel that making use of any appropriate services is unnecessary (GKV Spitzenverband 2011).

It would make sense to have low-threshold and accessible services which in particular take into account the often difficult situation in which carers live (older women with multiple health issues, limited resources, no partner, a lack of social support, low mobility etc.). Individual care and support concepts are of particular importance due to the respective special conditions and requirements in play. It is in this context that the recommendation is to be understood of further developing care consultancy in the sense of individual case management and to create structures in order to make such services available to all persons in need of long-term care and their family and friends (Klie et al. 2011).

Looking after dementia patients or other persons who are considerably restricted in their everyday skills is found to be particularly stressful by informal caregivers (Techniker Krankenkasse 2014). Especially with regard to this group of people it is the opinion of many stakeholders that the current legal definition of being in need of long-term care is too narrow: It is used to establish a long-term care requirement based on bodily functions and according to time constraints and does not do justice to social and

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**Figure 7**

Association between various health indicators and care workload (at least 2 hours per day). Results of binary logistic regressions separated according to gender, given age control, education, employment and social support data source: GEDA 2012

<table>
<thead>
<tr>
<th>Odds Ratio (95%-CI)</th>
<th>No sport</th>
<th>Hazardous alcohol consumption</th>
<th>Smoking</th>
<th>Dental check</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
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<td>2</td>
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<td></td>
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<tr>
<td>0</td>
<td></td>
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</tbody>
</table>

Care workload: At least 2 hours per day (Reference: Non-carers)
communicative needs especially of cognitively impaired persons. A new definition of long-term care dependence is expected at the end of this government’s term of office in the form of the Second Act to Strengthen Long-term Care which should be in force from 2017 (Bundesministerium für Gesundheit 2015, Gerlinger, Röber 2014). By taking greater account of the needs of cognitively impaired individuals in the assessment of care dependence significant stress-relieving stimuli are also to be expected for informal caregivers.

Changing framework conditions for the long-term care of those in need result from the demographic ageing of the population (Nowossadeck 2013): The growing gap that according to forecasts will exist between demand for and supply of carers also involves informal caregivers albeit to a potentially lesser degree. In the future there will be an increasing number of elderly people on the one hand and fewer younger people on the other with the latter possibly needing to assume the care of their family and friends in case of need. It is therefore all the more important to further strengthen the informal care potential. To date, one of the main areas of emphasis of the measures taken was on advice and training for those affected. Also the concept of family care leave from work will make it possible in the future for caring for family and friends to be more compatible with a person’s own employment situation. These analyses suggest that in the future we should pay more attention to approaches to strengthen social integration and to promote the health and well-being of informal caregivers as additional options for social intervention.

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