

ZQP ANALYSIS

Medication in Home Care from the Perspective of Caregiving Relatives

Study design

Quantitative population survey of caregiving relatives

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I. Survey Background

Medication poses a particular risk to elderly people in need of care

Elderly people in need of care are often confronted with various and significant health problems (Blüher, Schnitzer & Kuhlmeier, 2017). For more than 90% of the people over the age of 60, medicines are therefore part of their everyday life (Schwinger, Jürchott & Tsiasioti, 2017). Medicinal products can especially support the healing of acute illnesses or help people with chronic or advanced health issues to live sufficiently well with the resulting challenges. Medication in turn results in a number of potentially significant health risks, particularly for elderly people in need of care (Schurig et al., 2018).

The population over the age of 65 is generally at risk of getting inappropriate medications (Amann, Schmedt & Garbe, 2012). For persons in need of care, also the likelihood of getting prescriptions for many different active ingredients over a longer period increases with age. According to statistics, about 55-70% of those in need of care who are older than 60 are prescribed five or more active ingredients. This is a higher proportion than in the same age cohorts who are not in need of care, where the share is 20-42% (Schwinger, Jürchott & Tsiasioti, 2017). This so-called polypharmacy increases the risk of medication errors and adverse drug reactions (Scheidt-Nave et al., 2010). In addition to prescribed medications, over-the-counter medications are used as well (Knopf & Grams, 2013). Patients who take more than nine medications at the same time therefore have a 32-50% risk of medication errors (Ahrens, 2003). Polypharmacy also increases the risk of an unwanted interaction if one of the prescribed medications is taken incorrectly (Ellenbecker et al., 2004).

Medication safety in home care is a particular challenge

The correct use of medications – from their prescription to their application – is, therefore, very important for the patient safety and consequently also for providing good health care to people in need of care. This applies especially to those in a home-care setting. They represent a group vulnerable to problems related to the medication process (Ahrens, 2003; Berland & Bentsen, 2017; Lang et al., 2015; Thürmann, 2018).

The particular challenge of home-care medication results in large part from its complexity. Additionally, people in need of care often need considerable help in procuring and using the prescribed medications because they are impaired in their mobility, motor functions and cognition. Several studies identify 20 or more individual steps in the out-patient medication process – from the doctor's prescription to collecting, storing, preparing, setting up, administering and taking the medication to controlling its effects. Physicians, pharmacies, outpatient nursing services, relatives, the patients themselves and possibly also other actors often cooperate in this process (Görres et al., 2018; Meyer-Masseti et al., 2012; Parand et al., 2018).

International research has identified numerous risk areas in the professional activities of outpatient carers in relation to medication management (Görres et al., 2018). These include the administration of inappropriate or wrongly dosed medications (Kovner et al., 2005; McDonald & Peterson, 2008; Taylor et al., 2009), correctly preparing and placing the medication (Meyer-Masseti et al., 2016), conflicts with people in need of care and their relatives about the nature, extent and application of the prescribed medication (Payne et al., 2015), misunderstandings when coordinating with other actors (Lang et al., 2015; Meyer-Masseti et al., 2016) as well as deficits in qualification or competence (Berland & Bentsen, 2017; Lednik et al., 2013; McDonald et al., 2008).

Caregiving relatives are relevant actors in the medication process

For a comprehensive understanding of home-care medication, it is not sufficient to exclusively focus on professional outpatient care. Of the approximately 2.6 million people in need of care in Germany who are cared for at home, two thirds are exclusively supported by caregiving relatives (Federal Statistical Office of Germany, 2018). For 2012, it was estimated that about 4.7 million people in Germany were caring for a relative (Wetzstein, Rommel & Lange, 2015).

Respectively, the overall role of informal carers in the management of medications at home seems to be rather important. Among other things, they pick up prescriptions at the doctor's, buy medication at the pharmacy and store, prepare and provide the medication. Likewise, caregiving relatives may be responsible for administering the medication, providing information on its effects and monitoring these effects (Smith et al., 2003; Look & Stone, 2018). So, they take on many tasks that have already been identified as high-risk activities in terms of medication safety in research on professional outpatient care. Many of them experience considerable challenges, particularly when the person in need of care is living with dementia (Gillespie, Mullan & Harrison, 2013; Maidment et al., 2016). Although such international research findings on the role of informal carers in the medication process are not directly transferable, they nonetheless provide relevant information about the challenges that this group might also face in Germany.

The role of informal carers for medication safety and identifying the need for support

There is growing evidence of how important safety in medication is for the well-being of people in need of care, but also how complex this dimension of patient safety seems to be in home care and how important informal carers are in this context. In fact, when relatives are involved in the care process, they often represent one or even *the* key actor in ensuring the proper use of medication for the person in need of care. Such responsibility can be burdensome and distressing (Adelman et al., 2014; Aston et al., 2017; Coleman & Roman, 2015; Reinhard, Levine & Samis, 2012).

In order to strengthen the safety of people in need of care and better support relatives, it is necessary to better understand the role of caregiving relatives in home-care medication management in Germany and what challenges they report¹. This ZQP analysis is meant to contribute to this.

¹ This also accounts for the often overlooked group of young carers, which has not been included in this study. Young carers to some extent also take on tasks in the management of the medication for chronically ill family members (Lux & Eggert, 2016; Nickels et al., 2018).

II. Methodology and Approach

The statistical population of this analysis is made up of persons aged 40-85 years in Germany who have been caring for someone for at least six months and at least once a week in their private environment who meets the following criteria: (i) at least 60 years of age, (ii) requiring care according to the Social Security Code, i.e. the person has been assigned a care grade (Pflegegrad) and (iii) is cared for at home and does not live in residential institution. The sample of $n = 1,011$ persons was drawn from a panel of approximately 80,000 German-speaking persons. Only those who belonged to the statistical population of interest were able to participate.

The online survey was conducted between 18 February and 15 March 2019. The sample was re-weighted according to combinations of age, gender and formal education to approximate the ideal of a representative sample as closely as possible. Re-weighting was based on the German Aging Survey 2014, a representative survey of people between 40 and 85 who live in private households in Germany (Klaus & Engstler, 2016). A special analysis of the distribution of combinations of age, gender and formal education in this group was kindly provided by the German Centre for Gerontology. The highest weighting factor is 1.78. The margin of error of the study in the total sample is +/- 3% points.

III. Results

Summary

This ZQP analysis examines the responsibilities of relatives in the home-care medication process for elderly people in need of care and their associated experiences and challenges. The medication process is the sequence from the prescription of a drug to its application. For this purpose, 1,011 caregiving relatives in Germany between the age of 40 and 85, who have regularly supported a person in need of care (60 years and older) for at least six months, were interviewed.

■ Medication management for people in need of care

87% of the interviewed informal carers stated that the person they take care of either completely or partially, regularly uses more than at least three medications. 55% report five or more medications. The latter can be considered polypharmacy, which entails particular risks for patient safety. 64% of respondents said that no professional carer of an outpatient service was regularly involved in providing the medication to the person in need of care, i.e. that there is apparently no professional care support regarding the use of medication.

■ Participation of caregiving family members in the medication process

76% of respondents are regularly involved in the medication process and often or always take over more than three tasks. The extent to which the support succeeds also contributes to the success of the pharmacological treatment and the patient safety. Tasks related to medication in which relatives often give support are, for example: (1) “getting medication from the pharmacy”, 53% | (2) “picking up prescriptions at the doctor’s”, 47% | (3) “preparing medication”/“informing about medication”, 39% each | (4) “reading up on possible health consequences of the prescribed medication” 38% | (5) “setting up the medication”/“reminding the person in need of care to take medication”, 34% each.

■ Challenges in the medication process

The tasks involved in the medication process can be challenging and burdensome to caregiving relatives. The analysis shows that 63% of respondents involved in providing medication cover areas they perceive as difficult. 23% rate such tasks as rather or even very burdensome. 77% of respondents report that at least one medication problem occurred in the past six months. 35% say that this happened sometimes or even often. The following issues were reported most frequently: (1) a required “medication was used up”, 51% | (2) “a medication was used at the wrong time”, 36% | (3) “the person in need of care refused the medication”, 33% | (4) “doubt whether the drug was indicated”, 32%. The respondents also mention coordination problems with other actors and wrong dosages. Such problems, irrespective of whether the relatives noticed them in other actors or in their own actions, are potentially relevant to the safety of the person in need of care. To be confronted with these problems can, however, also contribute to burdening the caregiving relatives.

1. Medication management for people in need of care

- 87% of respondents stated that the relative in need of care regularly uses more than two medications.
- 55% stated that five or more medications are regularly taken or applied.
- In 64% of cases, no professional carer of an outpatient service was regularly involved in providing medication to the person in need of care.

61% of the caregiving relatives between 40-85 years of age, who were interviewed for the study, are women and 39% are men. Proportionally, they belong to the following age groups: 38% are 40-54 years old, 41% are 55-69 years old and the remaining 21% are 70-85 years old. The respondents have regularly supported the person in need of care for at least six months, two fifth (38%) for six months to two years, just under one third (30%) for between two and four years, and nearly another third (31%) for more than four years (figure 1).

How long have you been looking after the person in need of care who you help or care for at least once a week?

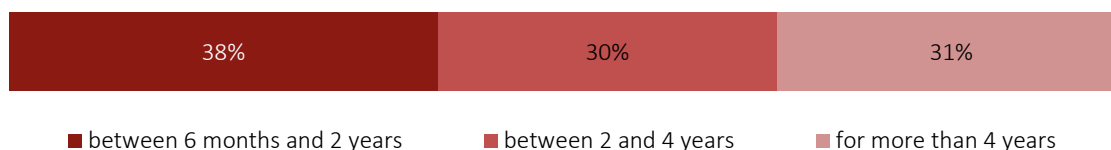


Figure 1: ZQP Survey of caregiving relatives between 40 and 85 years of age who have regularly supported a person in need of care for at least six months (n = 1,011).

Nearly a quarter (23%) of the respondents spend at least one hour on help and care during a typical week. The majority of the caregiving relatives (46%) stated that they look after the person in need of care for at least one hour several times a week but not daily. 18% help daily for up to three hours, and another 6% help between three and six hours every day. The other 8% of respondents state that they give care for more than six hours every day. 40% of the caregiving relatives describe the condition of their own health as “very good”, 38% as “satisfactory” and 22% as “not good/bad”.

Nearly a third (32%) of the respondents care for a male and a just over two thirds (68%) for a female person in need of care who is at least 60 years old. The need for long-term care is divided according to its socio-legal definition as follows: 12% have care grade 1, 41% care grade 2, 31% care grade 3, 12% care grade 4 and 4% care grade 5. According to the respondents, one in three (33%) of the persons in need of care has been diagnosed with dementia. 45% of those in need of care live alone at home. 15% live exclusively with the caregiving relative who participated in the survey and another 13% live together with the caregiving relative and another person. 27% live with at least one person, but not the carer who participated in the study.

The present survey also asked for the number of prescribed medications that are used on a permanent basis. Only 3% of respondents say that the person in need of care does not permanently use any prescribed medication. One in ten (9%) answered that there were one to two drugs. 35% report three to four drugs. Over half of the respondents (47% plus 7%) say that the person in need of care uses five or more medications on a daily basis (figure 2).

People in need of care often have to use medication, for example pills, drops, syringes, ointments, etc. [...] How many different medications prescribed by the doctor does the person in need of care regularly take per day?

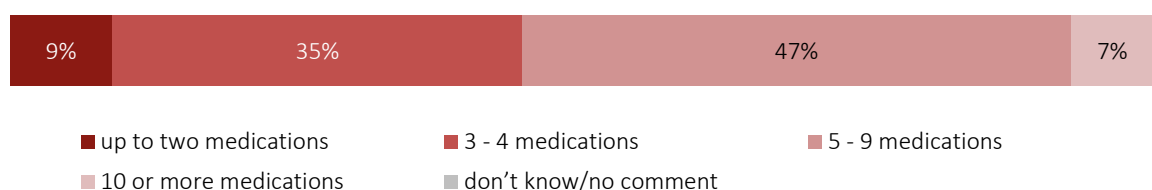


Figure 2: ZQP Survey of caregiving relatives between 40 and 85 years of age who have regularly supported a person in need of care for at least six months (n = 1,011).

According to the relatives, the men in need of care (60%) receive five or more medications more often than the women (53%). Similar but not significant differences are apparent regarding the care grade (51% for care grade 1 as compared to a steady increase to 58% for care grade 5) and diagnosed dementia (57% as compared to 51% without dementia). The age of the person in need of care, however, does not make a difference.

It is not only the number of medications, but also the different types that influence a successful medication process. Caregiving relatives are confronted with different dosage forms in the medication process for the person in need of care (figure 3). As might be expected, pills are used in almost all cases (99%). Ointments (28%), drops (22%) and/or syringes/pens (16%) are also mentioned quite often with at least one other dosage form being used in addition to pills in more than half of the cases (53%). Caregiving relatives therefore require knowledge and skills far beyond the use of pills. The storage, dosing, or application of ointments, drops, or syringes sometimes pose quite different requirements than pills. The overall process can become more complex and susceptible to errors when different products are used.

People in need of care often have to use medication, for example in the form of pills, drops, syringes, ointments, etc. [...] Which forms of medication do they use? (multiple answers are possible)

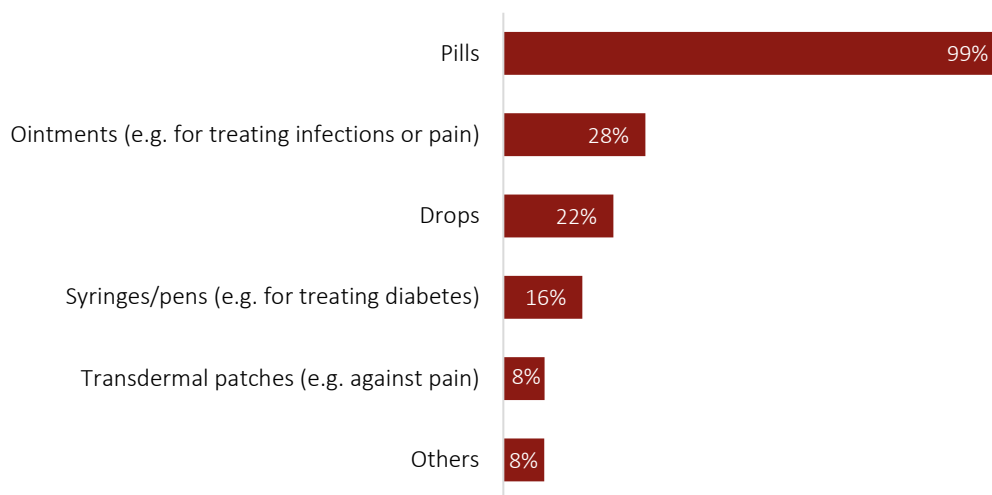


Figure 3: ZQP Survey of caregiving relatives between 40 and 85 years of age who have regularly supported a person in need of care for at least six months; filter: person in need of care regularly uses medicine (n = 981).

The analysis suggests that professional nursing care is seemingly not often made use of for providing the medication of people in need of care. It was stated by just under two thirds (64%) of the respondents that no outpatient nursing service was involved in providing medication for the person in need of care they support.

2. Participation of caregiving relatives in the medication process

- About three quarters (76%) of the respondents are regularly involved in the supply of medication to their relative in need of care. On average, they often or always perform 3.4 of such highly health-relevant activities.
- 80% of respondents help with the medication on a regular basis if an outpatient nursing service is not involved. The share is 82% among the respondents who reported that their relatives receive polypharmacy.
- The most common tasks related to medication supported by informal carers are: (1) “getting medication from the pharmacy”, 53% | (2) “picking up prescriptions at the doctor’s”, 47% | (3) “preparing medication”/ “informing about medication”, 39% each | (4) “reading up on possible health consequences of the prescribed medication”, 38% | (5) “setting up the medication”/ “reminding the person in need of care to take the medication”, 34% each.

Caregiving relatives play a central role in the home-care medication process. Over three quarters (76%) are involved on a regular basis, and this number increases to 80% if an outpatient nursing service is not involved. The respondents whose relatives in need of care use five or more prescribed medications are even more strongly involved in the medication process: 82% are involved in this process, which becomes ever more complex when the number of medications increases (figure 4).

[...] When you think about the past six months - which of the following individuals or groups of people have regularly participated in one or more of these activities related to medication for the person in need of care? Alternative answer: “I myself”

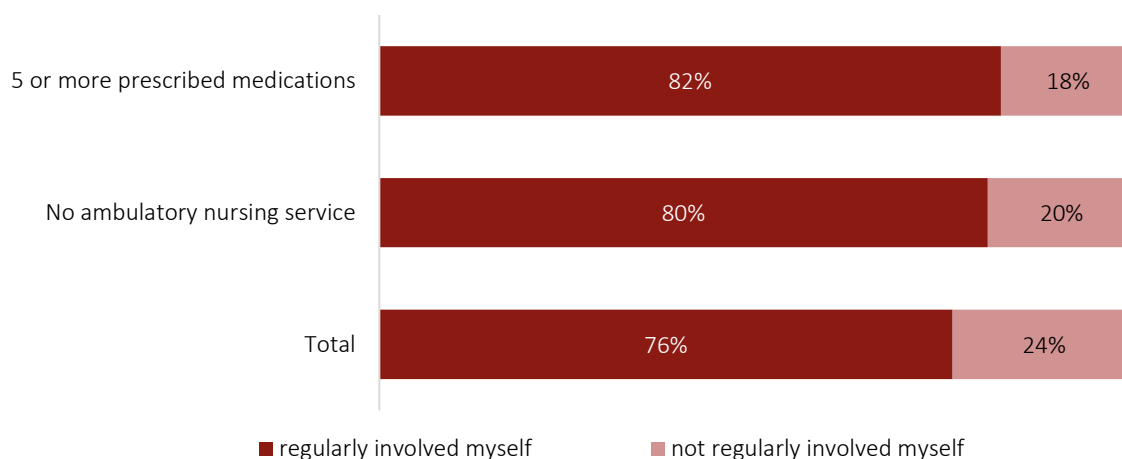


Figure 4: ZQP Survey of caregiving relatives between 40 and 85 years of age who have regularly supported a person in need of care for at least six months; filter: person in need of care regularly uses medicine (n = 981).

The supply of medication at home is characterized by an interaction of different groups of people (figure 5). According to the caregiving relatives, the general practitioner (82%) is most often involved, followed by themselves (76%). Just over one third of the respondents mentioned outpatient carers (36%) and friends, acquaintances and neighbours (35%).

[...] When you think about the past six months - which of the following individuals or groups of people have regularly participated in one or more of these activities related to the medication of the person in need of care?



Figure 5: ZQP Survey of caregiving relatives between 40 and 85 years of age who have regularly supported a person in need of care for at least six months; filter: person in need of care regularly uses medicine (n = 981).

To get a clearer picture of the importance of caregiving relatives in the home-care medication process, a closer look was taken at the range of their activities. Figure 6 provides an overview of the activities they “often” or “always” took over in the past twelve months. According to the carers, their most frequent tasks regarding medication are: (1) “getting medication from the pharmacy” (53 %), (2) “picking up prescriptions at the doctor’s” (47%), (3) “preparing medication”/“informing about medication” (39% each), (4) “reading up on possible health consequences of prescribed medication” (38 %) and (5) “setting up the medication”/“reminding the person in need of care to take the medication” (34% each).

When it comes to the medication of the person in need of care: Please tell us how often you performed the following activities in the past six months? [I have often/always done]

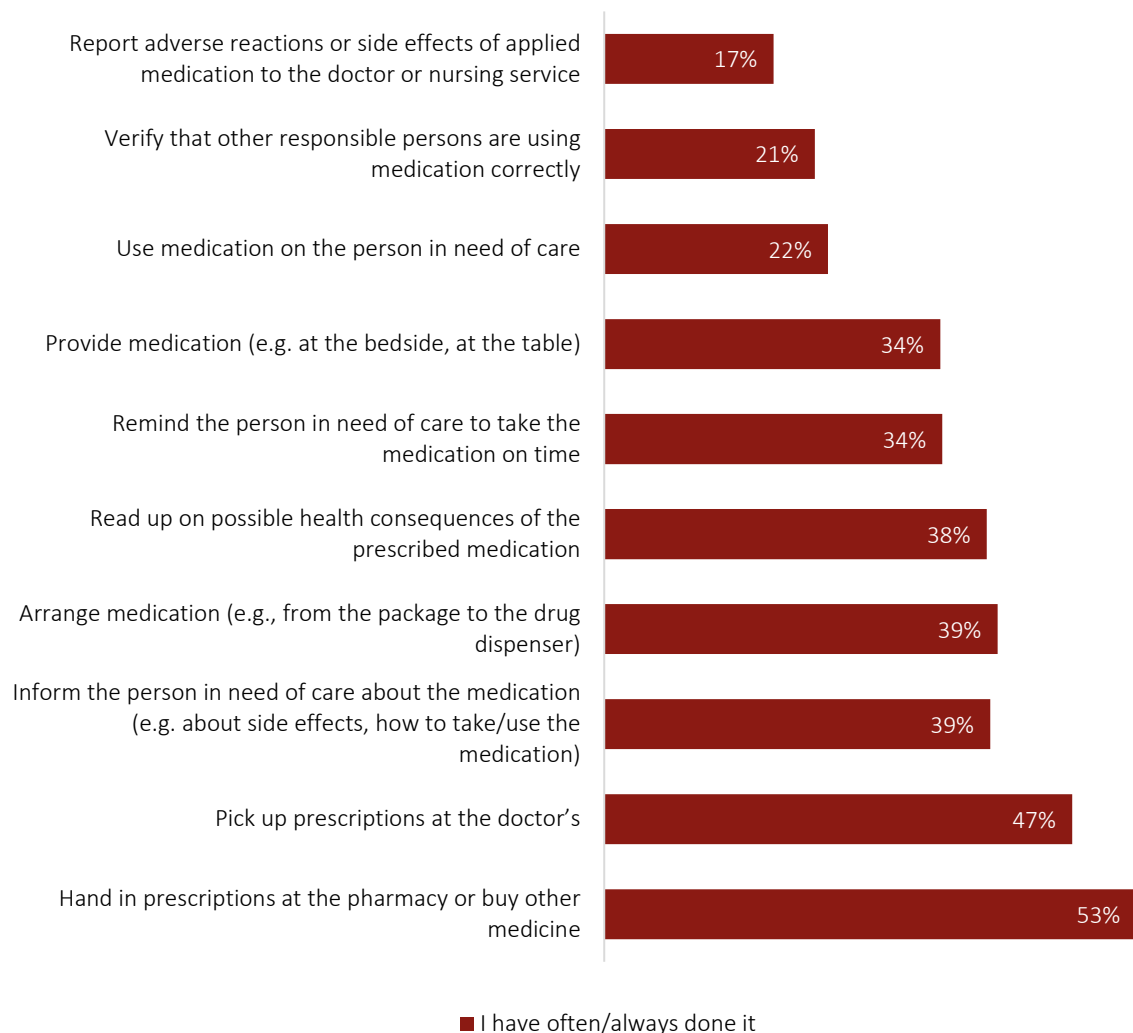


Figure 6: ZQP Survey of caregiving relatives between 40 and 85 years of age who have regularly supported a person in need of care for at least six months; filter: person in need of care regularly uses medicine (n = 981).

If only those activities in the medication process are counted that were “often” or “always” performed by the caregiving relative in the past six months, then they “often/always” carry out 3.4 activities on average (range 0-10). If the activities are considered that are “sometimes” or “rarely” taken over, the average increases to 7.6 activities (range 0 to 10).

3. Challenges in the medication process

- 63% of respondents take over tasks in the medication process that they perceive as very or rather difficult.
- 23% of the respondents tend to perceive at least one task as burdensome. Among those who perceive the tasks they perform as difficult these are 32%.
- 77% of all respondents reported that they know about at least one problem that occurred in the process of medication within the past six months.
- The most common issues were: (1) one of the required “medication was used up”, 51% | (2) “a medication was used at the wrong time”, 36% | (3) “the person in need of care refused the medication”, 33% | (4) “doubt whether the medication was indicated”, 32%.

Caregiving relatives play an important role in the medication process at home. But as how difficult and burdensome do they perceive their task? Nearly two thirds (63%) of the caregiving relatives, who are regularly involved in the medication process, perform at least one task that they describe as “very difficult/rather difficult”. The respondents mentioned particularly often (figure 7): (1) “explaining the medications” (45%), (2) “informing oneself about the consequences of prescribed medications” (34%), (3) “reporting adverse reactions or side effects of medications” (32%) and (4) “verifying the correct use of the medication by other responsible persons” (27%). The first two activities in particular are often performed by caregiving relatives (figure 6).

Almost a quarter of the caregiving relatives (23%) perceive the help they provide in medication as „very/rather burdensome“. When the caregiving relatives perform at least one activity that they regard as difficult, this share increases to almost a third (32%).

When difficulties and burdens are considered together, two thirds (66%) of caregiving relatives find support in the medication process difficult or burdensome.

When you think about the individual activities regarding medication management that you have just mentioned, how difficult are these activities? [I think it's very difficult/rather difficult]

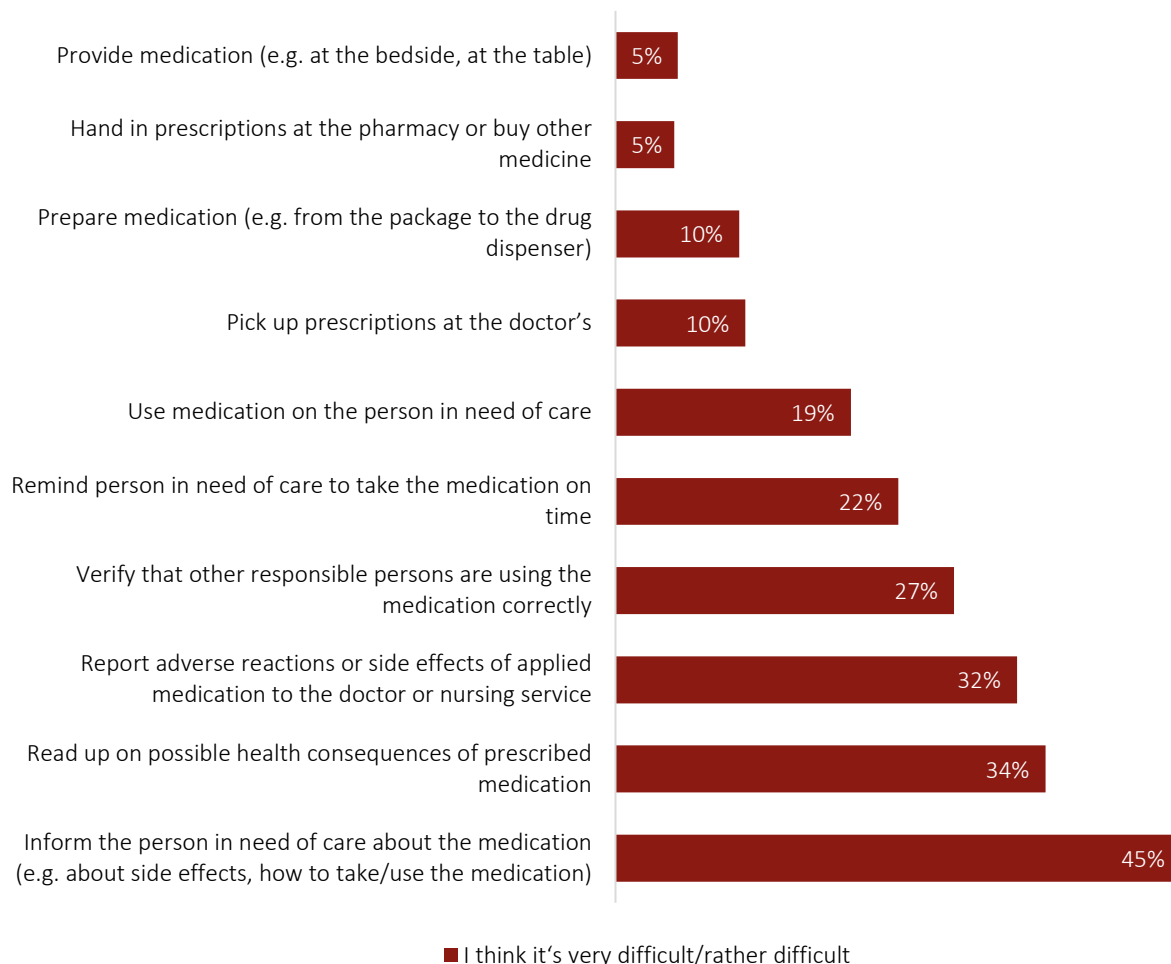


Figure 7: ZQP Survey of caregiving relatives between 40 and 85 years of age who have regularly supported a person in need of care for at least six months; filter: person in need of care regularly uses medicine (n = 981).

The caregiving relatives were also asked about problems related to medication management that may result in not administering the medication at all, not at the scheduled time, or not in the designated dosage. The most frequent problem mentioned by the respondents was the fact that a medication was used up (figure 8); almost two fifths (39%) answered that this rarely happened, 10% sometimes and 2% often. Other frequent problems were: “a medication was used at the wrong time” (36%), “the person in need of care refused the medication” (33%) and “doubt whether the drug was indicated” (32%).

It is sometimes not easy to ensure that the person in need of care uses all medications as planned. What problems have you experienced or observed in the past six months in the process of providing medication to the person in need of care?

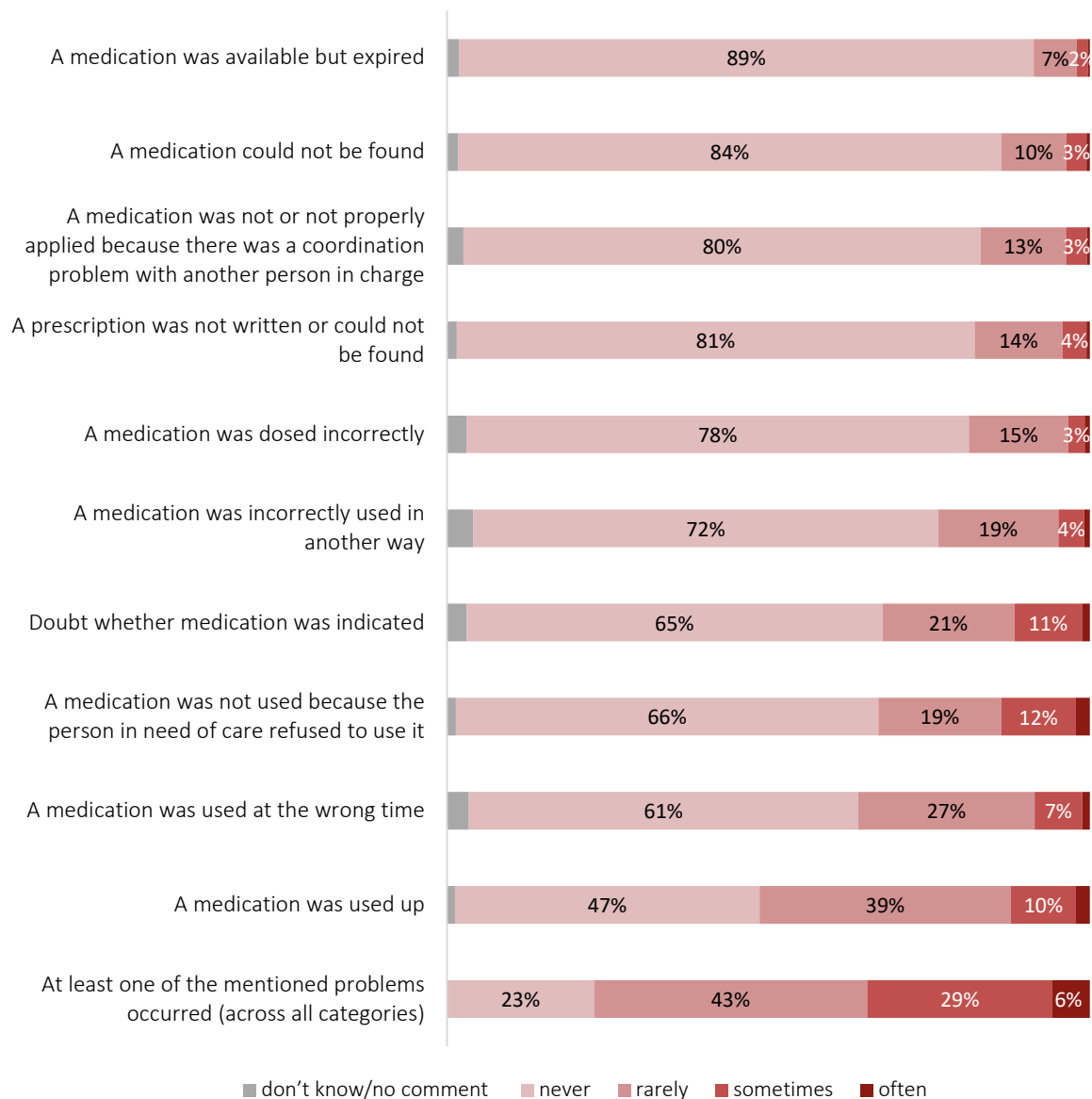


Figure 8: ZQP Survey of caregiving relatives between 40 and 85 years of age who have regularly supported a person in need of care for at least six months; filter: person in need of care regularly uses medicine (n = 981).

Since each of the ten problems mentioned above can lead to wrong medication, it was aggregated over all ten problem categories if at least one of the mentioned problems occurs “often”, “sometimes” or “rarely”. 6% of respondents stated that at least one problem category happens “often”. Another 29% reported that at least one of the categories occurs “sometimes” and 43% said it occurs “rarely”.

Misunderstandings and a lack of coordination between the persons involved in medication facilitate medication errors. Coordination between the people involved in medication is therefore important for a safe medication process in home care: 17% of the caregiving relatives, however, reported that a medication was not or not properly applied because of coordination problems with other people in charge. There is a higher percentage in those cases where an outpatient nursing service and/or other relatives, neighbours or friends were involved. When outpatient nursing services are involved, it is 26%, when neighbours, friends, or other relatives are involved, it is 25%. The more people support the medication process, the more it is prone to coordination problems: 10% of respondents report coordination problems when one or two people are involved, 18% experienced them when three to four people were involved and 37% when five or more people were involved in the process.

The same correlation emerges when the number of people involved is differentiated according to the occurrence of at least one of the ten problems mentioned (figure 9). While the proportion of respondents who have observed or experienced at least one problem “often” or “sometimes” is just over a quarter (4% plus 24%) when one to two groups of people are regularly involved; it increases to over two-fifths (11% plus 32%) with five or more groups of people.

Number of groups of people regularly involved in the supply of medication differentiated by the frequency of occurrence of at least one observed or experienced problem in the supply of medication for the person in need of care

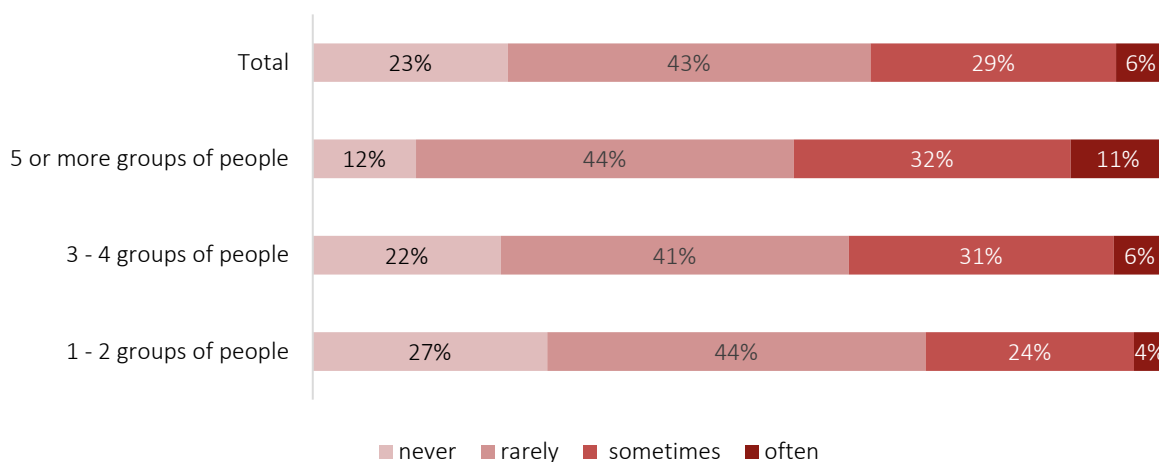


Figure 9: ZQP Survey of caregiving relatives between 40 and 85 years of age who have regularly supported a person in need of care for at least six months; filter: person in need of care regularly uses medicine (n = 981).

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