

From the report: People with dementia living alone in Denmark – Who are they, what challenges do they face, and what support do they receive in their daily life?



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*From the report: People with dementia living alone in Denmark – Who are they, what challenges do they face, and what support do they receive in their daily life? – English version of conclusion and recommendations*

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# English version of conclusion and recommendations

This document contains an English version of Chapter 6 "Conclusion and recommendations" of the report "People with dementia living alone – Who are they, what challenges do they face, and what support do they receive in their daily life?"<sup>1</sup>. Please see the report for a more detailed description of the data basis, definitions and analyses that comprise the basis of the conclusion and recommendations.

By Maya C. Flensburg Jensen, Jane Greve and Mads Ulrich Matthiessen

## Background and aim of the report

People with dementia living alone comprise a group of people about which we have little knowledge, in spite of the fact that both Danish and international research indicates that this group is particularly vulnerable and will constitute an increasingly large share of the population in the future, as the population lives longer. By commission of Alzheimerforeningen (the Danish Alzheimer Association), and with support from the Danish foundation TrygFonden, VIVE has carried out the project *People with dementia living alone*. The aim was to provide insight into the challenges that characterise this target group, as well as a basis for Alzheimerforeningen to develop further central activities targeted at persons with dementia living alone.

The report has contributed to this aim using a mixed-methods design. Registry data were used to characterise the group of persons with dementia living alone demographically and in terms of socio-economic status and health care use. Furthermore, a survey among the aging population and a qualitative case study of eight persons with dementia living alone was used to shed light on the daily life and well-being of people with dementia living alone, including what emotional and practical challenges they encounter and what support they receive in their daily life.

### Definitions

In this report, the group of persons with dementia is defined as persons who are registered with a dementia diagnosis in the National Patient Register (primary diagnosis) and/or are registered as undergoing treatment with medication for dementia. Using this definition, we arrive at a population group of 26,145 persons, which is a smaller population than previous investigations have used (Stevnsborg et al., 2016, Jensen-Dahm et al., 2015, Nørgaard et al., 2016, Nørgaard et al., 2017, Zakarias et al., 2016; Jørgensen, Walde-mar, 2014). When we use the phrase "persons living alone", we are referring to people who live alone and do not live in a nursing home or a care home. Using this delimitation, we find that 27.7% of the whole population of persons with dementia live alone. When we use the phrase "not living alone", we are referring both to persons living with a partner and persons who live with another family member or in shared accommodation. Furthermore, the report focusses on persons in the age range of 55-93 years.

## Who are the persons with dementia living alone?

This section gives an overview of the overall answers we can provide to the question of who are persons with dementia living alone.

*People with dementia living alone are older and are primarily women.* People with dementia living alone are older than the group of people with dementia not living alone. The group is also characterised by having a large share of women. Among men with dementia between the age of 55 and

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<sup>1</sup> We have added a definition box and an appendix with two figures, which are not in the original Danish version of the chapter.

93, 28% live alone, while the figure for women is 60%<sup>2</sup>. The longer life-span of women relative to men increases women's risk of getting dementia and thus explains why there are more women than men among people with dementia living alone.

*People with dementia living alone have a lower socio-economic status than people with dementia not living alone.* Both men and women with dementia living alone more often belong to the lower socio-economic groups than the people with dementia who do not live alone. A larger share do not have a qualifying education, a larger share are without employment, and a larger share are in the lowest segment of the income distribution. These differences between people living alone and not living alone also exist in the general population. Moreover, among both men and women with dementia a smaller share of those living alone own their residence than among those not living alone.

*People with dementia living alone less often live in rural areas than people with dementia not living alone.* There is a tendency for people with dementia living alone, both among men and women, to live in rural areas less often and live in the capital area more often than people with dementia not living alone.

*People with dementia living alone have more or less the same level of health care usage as people with dementia not living alone.* Generally, there are only minor differences between people with dementia living alone and those not living alone with regard to their use of health care services. For both men and women, there are only small and non-significant differences between the two groups with regard to the share that have been admitted to a hospital due to somatic and psychiatric disorders. However, a larger share of men with dementia living alone have been admitted to hospital due to psychiatric disorders than men with dementia not living alone. Men with dementia living alone and not living alone have almost the same average number of yearly visits to a general practitioner. Women with dementia living alone see a general practitioner 1.4 times more per year, on average, than women with dementia not living alone.

*People with dementia living alone are more often treated with psychiatric medication than people with dementia not living alone.* The share treated with psychiatric and analgesic medicine is significantly larger for persons with dementia than for persons without dementia, larger for women than for men and larger for people living alone than for people not living alone. However, the share treated with psychiatric medication among men with dementia is approximately the same for persons living alone (44%) and persons not living alone (43%). Generally, the share treated with psychiatric and analgesic medicines increases with age. Among women with dementia living alone, 55% are being treated with psychiatric medication. The corresponding share among women with dementia not living alone is 51%, and for women without dementia living alone and not living alone it is 25% and 14%, respectively.

We have summarised the results of the registry data in appendix A.

### **What characterises the daily life of people with dementia living alone?**

For the analysis of the daily life of people with dementia living alone, we used both a qualitative case study and a survey investigation. In the sections below, we draw threads across the two analyses to provide an overall answer to the two sub-questions of a) what concrete challenges persons with dementia living alone encounter in their daily life, and b) what support they receive in their daily life. It is important to note that neither the case study nor the survey are representative of the registry population. Rather, they are primarily based on replies and narratives from persons with mild to

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<sup>2</sup> A large share of men with dementia, 66%, live with a partner. Only 36% of women with dementia live with their partner. Among both men and women, around 5% live with a person who is not their partner. Among people without dementia, 23% of men and 37% of women live alone.

moderate dementia who are younger than the average age, so that they presumably do not represent the most vulnerable group among persons with dementia living alone.

*What challenges do persons with dementia living alone encounter in their daily life?*

The qualitative case study shows that when you ask the eight persons with dementia living alone how they manage, their immediate response is that they manage very well – better than others – and therefore generally do not feel that they have significant challenges in and around their home. However, the case study shows that this immediate response, which previous studies have also shown, to a great extent reflects a lacking problem recognition. When you spend more time with them, it soon becomes clear that they are all challenged in their daily life.

*Functional impairment(s).* What these eight persons feel gives the most frustration and challenges in their daily life is their functional impairment, because it is the functional impairment that is seen as preventing them from living their daily life in and around the home as they would like to. Thus, all eight persons describe having *physical functional impairments* (e.g. poor balance, poor health, lack of energy), *mental functional impairments* (e.g. poor memory, confusion, anxiety) and/or *social functional impairments* (e.g. impaired language and ability to function when surrounded by a large number of people) – or in other words that they are both physically, emotionally and/or socially challenged in their daily life. These are challenges that are not closely related to their dementia diagnosis but are also affected by other parameters, for instance by their somatic problems (several of them had diabetes, heart problems etc.).

*Practical challenges in the home.* The case studies show that the functional impairments mentioned above – mainly the mental and physical ones – lead to practical challenges in the home for the eight persons with dementia living alone. Even though the eight persons handle a lot of the practical tasks in the home themselves, the case study shows that they all struggle, to varying degrees, with one or more of the following tasks: cooking, nutrition, shopping, finances, staying on top of their daily life, transport, personal hygiene and cleaning, outdoor maintenance and avoiding falls or getting lost.

*Loneliness issues and challenges related to living alone.* The survey analysis shows that a larger share among the people living alone (both with and without dementia) express yearning for the company of others when they are alone than among those not living alone. While this does not necessarily mean that they are lonely, it does indicate that there may be an issue related to loneliness. The case study thus also shows that three of the eight persons have experienced feeling lonely – a feeling that might have been augmented by, but cannot be solely due to, either the dementia or living alone. For example, one of the persons had felt lonely all his life. However, the case study also shows that the professionals, especially the dementia coordinators for the eight persons with dementia living alone, are very much aware of the risk of loneliness – a risk that they – in line with the results of the survey – felt was increased by them living alone (and the dementia). Therefore, one of their main areas of focus was also to mobilise the persons with dementia living alone to take part in social activities.

The case study shows, however, that living alone was not only seen as negative, but rather that it was experienced differently by the case persons. In particular, the three male case persons with dementia felt a certain sorrow over living alone, while the women seemed to have accepted the status of living alone to a greater extent. Some of the women stated that they had actively chosen not to have a man in their life to make it easier for them to handle their dementia, e.g. because it

made it easier for them to decide how to structure their daily life themselves<sup>3</sup>. However, both men and women stated that the lack of company at meals led to less motivation to cook.

*Sad, afraid and worried?* The survey analysis shows that persons with dementia living alone generally state being less sad, afraid and worried than persons with dementia not living alone. Conversely, persons without dementia living alone are more sad, afraid and worried than persons with dementia living alone. This could be an indication that people are sad, afraid and worried to a lower extent if they have dementia and live alone than if they do not have dementia and live alone. However, one should show caution in making such a generalisation, as these differences could be explained by, for instance, gender and age differences in the groups. Among the respondents with dementia living alone, the share of women is 17 percentage points higher than the share among those without dementia living alone, and, on average, the respondents with dementia living alone are 11 years older than those without dementia living alone. The case study of the eight persons with dementia also shows that especially one of the women felt very insecure in her home and was afraid of being robbed.

#### *What support do people with dementia living alone get in their daily life?*

As described above, persons with dementia living alone can be both physically, emotionally and/or socially challenged in their daily life. It is these challenges that can prevent them from living the life they want in and around their home. However, both the case analysis and the survey analysis also give an insight into the support that persons with dementia living alone can receive in their daily life, which can be an important means to limit their challenges.

*Contribution of type of residence to support.* The qualitative case analysis indicates that the type of residence that the persons with dementia living alone live in affects how physically, emotionally and/or socially challenged they feel they are in their daily life. Six of the eight persons connected to the case study have moved to an elderly or handicap-friendly residence or would like to do so. What is seen as attractive is either the social possibilities provided by this type of residence (often, several people are at home in the daytime), the shorter distance to the family and shops, the handicap-friendly interior (no door thresholds, sliding doors etc.) or the smaller living space or outdoor space. With the exception of one person (who was prepared to go into a nursing home), it was also the persons living in this type of residence who seemed to manage the best in both practical and emotional terms, even though the actual move had often been a challenge and all their problems were not solved by living in this type of residence.

The qualitative analysis thus constitutes an important supplement to our understanding of how persons with dementia living alone can be supported in relation to their choice of residence. Seven of the eight persons with dementia living alone generally expressed a strong desire to stay in their own home as long as possible, which confirms the findings of other international studies of persons with dementia living alone. In a Danish context, however, the findings specify that, in expressing this desire, the seven persons with dementia living alone<sup>4</sup> were referring to wanting to avoid moving into a nursing home as long as possible. In extension of this, several of their health care professionals cautioned against promoting the message of “as long as possible in your own home” in relation to this target group, because persons with dementia living alone can benefit greatly, both in practical

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<sup>3</sup> It must also be said, however, that all except one of the case persons have also lived alone for 6-30 years, and that the case person who had just lost her husband is especially challenged in practical matters, because he took care of some things that she was unable to.

<sup>4</sup> At the time of the case visits, the eight persons lived in terraced houses (1 person), summer houses (1 person), cohousing communities (1 person), rented apartments (1 person) and elderly or handicap-friendly residences (4 persons).

and emotional terms, from moving to another type of residence that caters more for their functional impairment(s), before the dementia becomes too advanced.

*Practical support in the home.* The qualitative case analysis indicates that persons with dementia living alone receive relatively little help and support in the home. The analysis shows that the persons with dementia living alone either spend a lot of energy on managing the practical tasks in the home themselves, do not manage the tasks (e.g. eat yoghurt as their main meal or lower cleaning standards) or to varying degrees draw on their children, technology (iPads, alarms, electronic calendars etc.), the health care professionals, neighbours or activity centres to manage the tasks. There seems to be a certain division of labour in relation to which actors give which support in the home. Generally, *children* help with finances, shopping, visits to the doctor, food and tidying up, *neighbours* help with outdoor maintenance, *activity centres* help with food, and the *health care worker* provides help in relation to especially medicine, but also cleaning<sup>5</sup>. The analysis also shows that most of them want to do as many things as possible themselves to keep going and often need to be persuaded to get help.

The survey analysis shows, in keeping with the qualitative study, that persons with dementia living alone get little help in the home. Only a small share of the persons with dementia living alone – between 8% and 20% – responded that they get help from their *relatives* with cleaning, washing, shopping or cooking, with maintenance of their residence or garden, with financial affairs or communication with the authorities, to go to check-ups, treatment and the like, and to get out of the house, go on visits or take part in leisure activities. Persons with dementia living alone, get considerably more help from relatives with financial affairs/communication with the authorities (28%) than do persons with dementia not living alone (13%). However, 72% of the persons with dementia living alone still do not think they get help with these tasks. As described above, the qualitative case analysis gives the same impression of the relatives' (especially the children) help with financial affairs and communication with the authorities, but the case study indicates that all of the eight case persons receive this kind of help from their relatives. The different indications of the qualitative data and the survey investigation with regard to the amount of practical help may either be due to the eight case persons getting more help than average, or it may reflect that the persons who answered the survey analysis belong to a select group that, for instance, is better off than average and thus has relatively little need of help with these activities.

*Social contact and leisure activities.* The survey analysis shows that both persons with dementia living alone and not living alone take part in many leisure activities – and almost to the same extent as persons without dementia. While the share of the persons in the survey with dementia living alone who answered in the positive to the questions about out-of-home physical activities such as walking and biking is smaller than for people with dementia not living alone, persons with dementia living alone and not living alone have the same tendency to engage in planned physical activities, such as exercising and other kinds of sport. Compared to persons with dementia not living alone, there is also a larger share among persons with dementia living alone who go to a senior club and leisure classes.

The qualitative case analysis shows, in keeping with the survey analysis, that most of the eight persons engaged in activities outside the home several times a week. In particular, the participation in activity and day centres was high, several of the persons went all day or several times a week (and, for instance, went on excursions, exercised or sang, got a hot meal etc.). It was clear that especially the dementia coordinators were an important reason why the eight persons had started

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<sup>5</sup> The home help assists seven of the persons with medicine and two persons with cleaning. However, one person receives private cleaning.



to use the activity centre, because they were the ones, due to their focus on loneliness, who had motivated them to go there. According to the dementia coordinators, there was often a great deal of initial resistance against going to the activity centre, but the majority of them enjoyed going there, which most of the case persons also confirmed. However, several dementia coordinators were also aware that a few case persons expressed not wanting to go the activity centre (any longer) and requested alternatives, e.g. volunteer visits for persons with dementia living alone.

The qualitative case analysis also shows that all eight persons had fairly frequent (daily or weekly) social contact with neighbours and relatives (especially siblings or children) – a generally reoccurring result in the survey investigation. In particular, the study showed that the daughters often came to the home and did things for their parents and went with them to the doctor (while the sons took care of more traditional and practical tasks, such as maintenance and finances). A notable issue, though, is the emotional frustration and strain that several of the daughters expressed in relation to the case study, and the dementia coordinator's pointing out of the limited possibilities there are of helping relatives of persons with dementia living alone (because most support schemes are targeted at cohabiting relatives).

*Transport.* The qualitative case analysis shows that a crucial factor for getting out of the house for the persons with dementia living alone is transport. Several of them have lost their driver's licence and need someone to drive them to get out of the house. However, they do not all feel that they have good access to transport.

*Support from professionals.* The case analysis shows that all of the eight persons with dementia living alone emphasised that their dementia coordinator and, for some, their contact person at the day centres were crucial sources of both emotional and practical support. It was clear that these persons were important in directing focus at the eight persons' functional impairment and problems – not least to find solutions to their problems. Cooperation between the dementia coordinator and the contact person also functioned as an important kind of support (because the contact person often had more frequent contact with the person with dementia living alone).

## **Recommendations**

The purpose of the project *Persons with dementia living alone* is to shed light on central issues relating to persons with dementia living alone that can be relevant to further development of central activities targeted at these persons. Overall, the project shows that *persons with dementia living alone* do not necessarily see themselves as a group with special needs or request help, which is important to consider in the way activities for them are designed, addressed and targeted. The mapping of the group of persons with dementia living alone also shows that several of their issues – e.g. in the form of their socio-economic status – are also issues that apply to the population of persons without dementia living alone, and thus seem to be related to the issue of living alone. On the other hand, the project shows that persons with dementia living alone can – perhaps due to their dementia – have difficulties expressing the problems they face in their daily life and finding strategies to handle them.

Thus, the project *Persons with dementia living alone* points to the possible advantages of carrying out a more systematic mapping of the functional impairments and support needs of persons with dementia living alone, e.g. using the Danish Dementia Research Centre's new method tool "The Conversation Wheel". Moreover, the project shows that there is a need for activities that can support persons with dementia living alone in and outside their home, and that a broad approach should be followed in the formulation of these activities. Persons with dementia living alone can both be in need of activities targeted at addressing or limiting the physical, mental and/or social functional

challenges they encounter in or around their home. Furthermore, the investigation draws attention to the need to support relatives of persons with dementia living alone – a support that is important to acknowledge because the relatives often play a crucial role in making the life of the persons with dementia living alone work.

To ensure that persons with dementia living alone manage in their daily life, VIVE recommends – in addition to a better (and possibly more cross-disciplinary) mapping of the needs of persons with dementia living alone – ensuring activities for persons with dementia living alone, both in and outside their homes, and that greater possibilities for mobility are created for persons with dementia living alone, e.g. in the form of better transport and housing possibilities.

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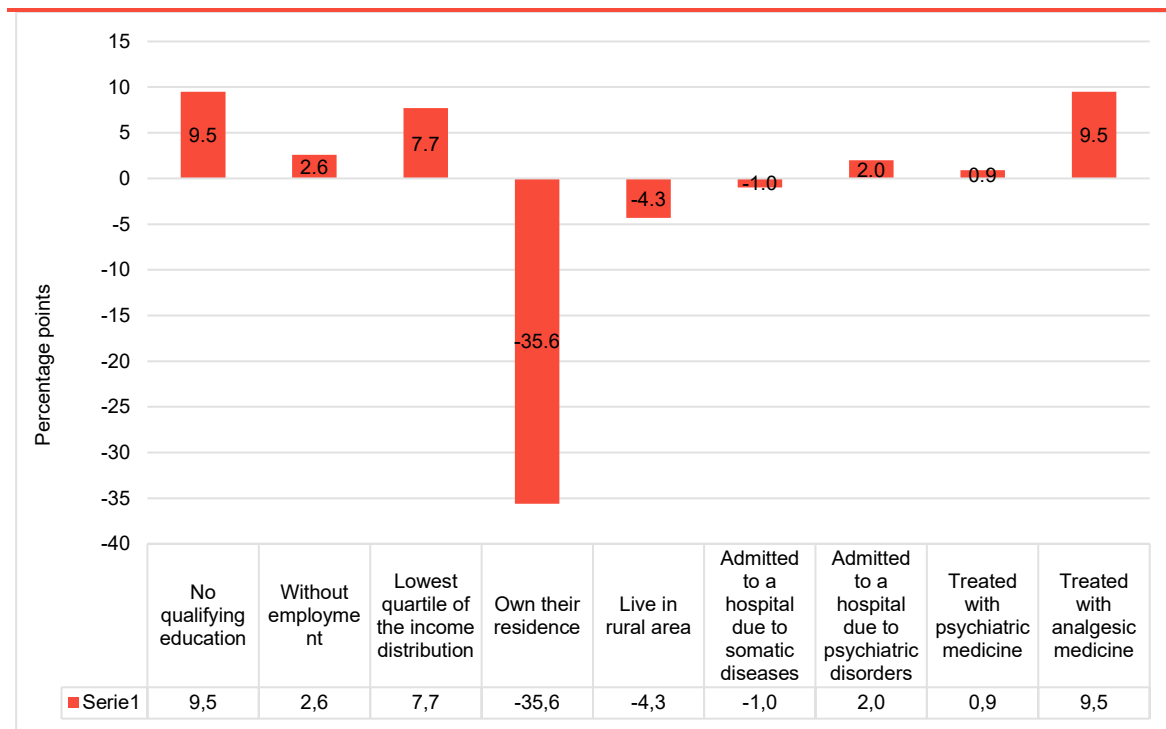
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# Appendix A

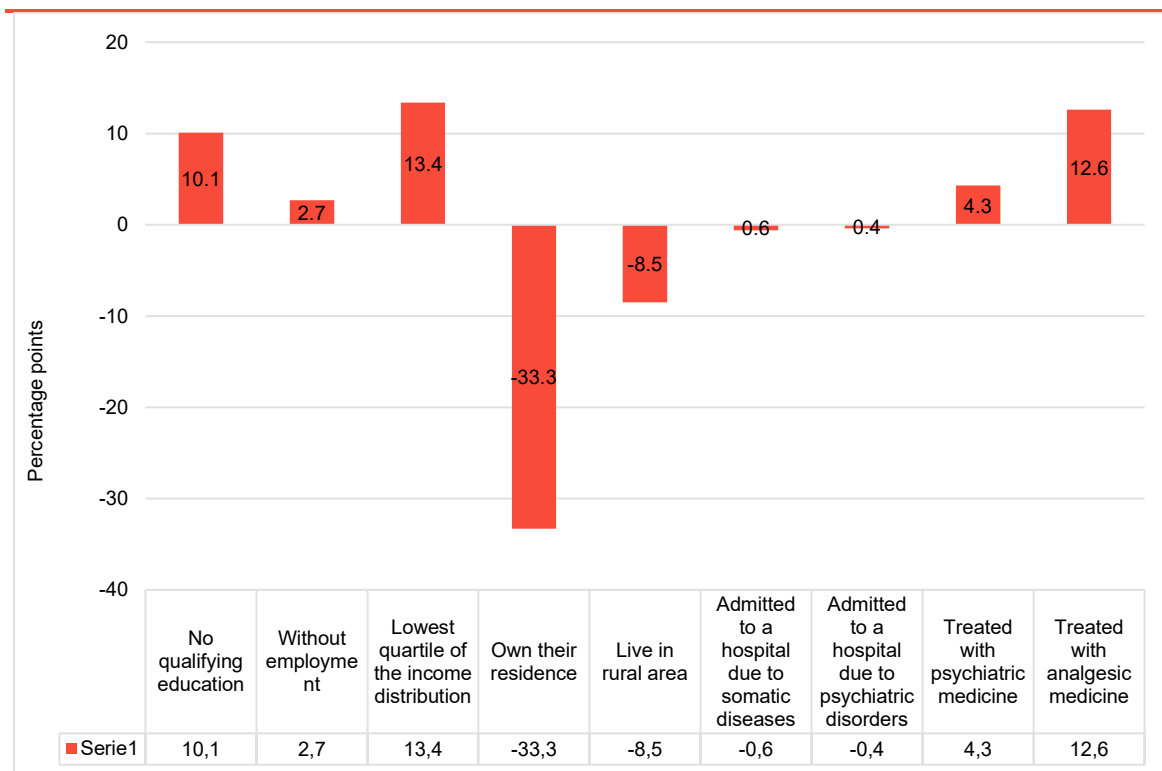
**Figure A.1** Share of men with dementia. Differences between men living alone and men not living alone.



Note: The sample includes 1,871 men with dementia living alone and 4921 men with dementia not living alone. For men with dementia living alone, 48.0% have no qualifying education, 94.0% are without employment, 42.5% are in the lowest quartile of the income distribution, 39.8% own their residence, 30.9% live in a rural area, and 47.6% have been admitted to a hospital due to somatic diseases. Also, 9.7% have been admitted to a hospital due to psychiatric disorders, 44.2% have been treated with psychiatric medicine, and 36.5% have been treated with analgesic medicine.

Source: Registry data.

**Figure A.2** Share of women with dementia. Differences between women living alone and women not living alone.



Note: The sample includes 5,381 women with dementia living alone and 3,615 women with dementia not living alone. For women with dementia living alone, 66.8% have no qualifying education, 98.3% are without employment, 54.4% are in the lowest quartile of the income distribution, 40.7% own their residence, 28.5% live in a rural area, and 44.1% have been admitted to a hospital due to somatic diseases. Also, 7.1% have been admitted to a hospital due to psychiatric disorders, 55.0% have been treated with psychiatric medicine, and 50.3% have been treated with analgesic medicine.

Source: Registry data.

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