Home care patients' experiences from living with polypharmacy - a qualitative interview study

Mannheimer, Stina Marie; Bergqvist, Monica; Bastholm-Rahmner, Pia; Gustafsson, Lars L; Vég, Anikó; Schmidt-Mende, Katharina

DOI: <https://doi.org/10.3399/BJGPO.2021.0181>

To access the most recent version of this article, please click the DOI URL in the line above.

Received 30 September 2021

Revised 17 November 2021

Accepted 30 November 2021

© 2022 The Author(s). This is an Open Access article distributed under the terms of the Creative Commons Attribution 4.0 License (<http://creativecommons.org/licenses/by/4.0/>). Published by BJGP Open. For editorial process and policies, see: <https://bjgpopen.org/authors/bjgp-open-editorial-process-and-policies>

When citing this article please include the DOI provided above.

Author Accepted Manuscript

This is an 'author accepted manuscript': a manuscript that has been accepted for publication in BJGP Open, but which has not yet undergone subediting, typesetting, or correction. Errors discovered and corrected during this process may materially alter the content of this manuscript, and the latest published version (the Version of Record) should be used in preference to any preceding versions

Home care patients' experiences from living with polypharmacy - a qualitative interview study

Stina Mannheimer, MD, Stockholm Region and Division of Family Medicine and Primary Care, Academic Primary Healthcare Centre, Stockholm, Sweden.

Monica Bergqvist, PhD, RN, Division of Nursing, Department of Neurobiology, Care Sciences and Society, Karolinska Institute, Stockholm, Sweden.

Pia Bastholm-Rahmner, PhD, Behavioural Scientist, Karolinska Institute, Division of Clinical Pharmacology, Department of Laboratory Medicine, Karolinska University Hospital Huddinge, C168, floor 6, Stockholm, Sweden.

Lars L Gustafsson, professor, MD, Karolinska Institute, Division of Clinical Pharmacology, Department of Laboratory Medicine, Karolinska University Hospital Huddinge, C168, floor 6, Stockholm, Sweden.

Anikó Vég, PhD, Pedagogue, Region Stockholm, Health Care Administration, Box 6909, Stockholm, Sweden.

Katharina Schmidt-Mende, PhD, MD, Karolinska Institute, Department of Neurobiology, Care Sciences and Society, mailbox 23400, Karolinska University Hospital Huddinge, Sweden. PhD, MD, Stockholm Region and Division of Family Medicine and Primary Care, Academic Primary Healthcare Centre, Stockholm, Sweden.

Abstract

Background: Patients with home care (HC) are frail and multi-diseased older persons who are often treated with many medicines. Their perspectives on polypharmacy have previously been sparsely explored.

Aim: To investigate these patients' experiences and perceptions regarding polypharmacy.

Design and setting: Semi-structured interviews with seventeen patients with HC in Stockholm, Sweden. The informants' median age was 83,5 years (range 74–97 years) and the median number of prescribed medicines was 11 (range 5-30).

Method: The interview questions were open and aimed to encourage informants to speak freely about their personal experiences of living with polypharmacy. Data was analysed using an inductive thematic analysis.

Results: Two themes were identified: 1) Experiences from daily life with polypharmacy, and 2) Dependency on the relationship to healthcare professionals. The first theme contains the main finding which was the diversity in how older persons experienced polypharmacy and how they coped with polypharmacy in everyday life. While some were satisfied despite having multiple medicines, others experienced such psychological unease due to polypharmacy that it led to reduced quality of life. The second theme reflects the importance

of the relationship between the older person and healthcare professionals for medicine-related ideas and attitudes.

Conclusions: The individual variation in experiences regarding polypharmacy points to the value of interprofessional teamwork with the patient as an active partner. Therefore, healthcare professionals need to adapt a more person-centred approach where the patient's perspectives are respected and considered in medicine-related decision-making.

Keywords: general practice, health services for the aged, polypharmacy, multimorbidity, frailty, psychosocial functioning

How this fits in

A limited number of qualitative studies on how older persons perceive polypharmacy have been conducted before. However, few have had informants as frail and multimorbid as HC patients. Given an aging population and widespread use of multiple medicines, knowledge on how this group experience polypharmacy is crucial to improve conditions for person-centred care and thus enhance health outcomes.

Introduction

Prescriptions of medicines to Swedish persons over 75 years of age have increased by approximately 60% since the beginning of the 1990s (1), and every second uses at least five medicines (2). Likewise, the occurrence of polypharmacy is widespread among older adults throughout high income countries (3, 4). While polypharmacy may be appropriate and improve health, the risk for a range of adverse health outcomes is increased with the number of medicines used, particularly for multimorbid older patients (3). Older persons often trust general practitioners' (GPs') expertise regarding medicines (5, 6). Still, complex medicine regimens and uncertainties in decision making are perceived as challenging by many older patients as well as GPs (7). Several studies reveal dislike or even reluctance regarding intake of medicines and a preference to take as few medicines as possible (8). Older persons may refrain from sharing information about own initiatives to discontinue medicines with their GP (9), which can be hazardous. Previous research highlights the need for improved communication between primary healthcare professionals and older patients by making therapeutic relations more horizontal (10), which implies that healthcare professionals must support older persons to manage drug therapy based on their own conditions. Home care (HC) patients are a group of particularly frail older persons (see Box 1), for whom polypharmacy is rule rather than exception. We are not aware of any previous study exploring HC patients experiences of polypharmacy. However, this matter is important in order to improve patient-healthcare relations and quality of care.

Methods

Study design

We explored how HC patients experience their drug therapy with focus on living with polypharmacy. According to our aim, we chose a qualitative study design with inductive thematic analysis (15) of semi-structured interviews (16). We followed the Consolidated criteria for reporting qualitative research (COREQ) (17).

Selection of informants

The research team contacted primary healthcare practices in suburban areas with different socioeconomic status in the Stockholm Region. Through local HC nurses we got in contact with HC patients with at least five prescribed medicines who were assumed to be able to participate in a longer interview, which required a sufficient verbal and cognitive ability and no dementia diagnosis or advanced stage of terminal illness. Of 19 respondents, 18 agreed to participate and were scheduled for an interview. Due to hospitalization of one patient 17 interviews were finally conducted, of which 6 were with men (median age 84,5) and 11 with women (median age 82). For informant characteristics, see Supplementary box 1.

Data collection

The individual interviews were conducted in the patients' private homes in 2018 and 2019. The interviews were conducted by four persons: SM (resident GP), KSM (GP), PBR (behavioural scientist) and JS (resident GP). None of the interviewers had any kind of relationship with the informants and had not met them prior to the interviews.

To understand different aspects about how the patients experience their drug therapy the interviews started with broad open-ended questions (see Supplementary box 2 for interview guide). Based on the answers, follow-up questions were used to clarify and deepen the informant's answer. By asking questions such as, "What do you mean?" or "Could you give an example?" we gained information reflecting the informant's experiences on a deeper level. The interviews lasted between 35 and 75 minutes, were audio-recorded and transcribed verbatim. During the last interviews informants' comments tended to be redundant from data already collected, thus saturation was assumed (18).

Data analysis

From the empirical material, an inductive thematic analysis was carried out (15). In this approach, the categories and themes identified are strongly linked to the data without trying to fit them into a pre-existing theoretical frame.

The phases of the analysis were as follows:

1. The transcripts were read several times by two researchers to acquire a good sense of the whole material.
2. Sections of text and key words in the transcripts, with focus on the aim of the study, were marked and coded. Marked sections with related topics were grouped into categories. Categories were then compared for emerging patterns of similarities and differences, which was carried out separately by two researchers and then discussed.
3. The next step was to find related patterns within each category. Certain categories were considered to have a common origin, were related or both. When opinions differed between research members, we returned to the transcripts and discussed them until an agreement was reached (negotiated consensus). This was a way to reach consensus of the findings and trustworthiness of the data analysis.
4. The categories were then merged into two themes. These themes are interconnected and cannot be seen as isolated because they are closely related to each other.
5. Quotes were selected to illustrate each category.

The data analysis was mainly performed by SM and MB (registered nurse). KSM, PBR and AV (pedagogue) took part in the analysis process of finding related patterns between the categories and themes through a reciprocal reading between transcribed text and the categories and themes. This is a way to increase the trustworthiness in the analysis process (19). All authors then acted as co-readers to finally discuss and refine the findings in relation to the research questions. The main aim of this process was to compare the results to determine whether any categories or themes were overlooked.

Ethical considerations

Oral and written informed consent was obtained from every participating patient prior to the interview as well as from the head physician at the patient's primary healthcare centre. Before each interview, the patients were again informed of the aim of the study and that participation was voluntary and could be discontinued at any time. After transcription, the identities of the informants were coded to guarantee confidentiality, and the audio files were removed.

Results

The analysis of 17 interviews with HC patients resulted in two themes with underlying categories (see Figure 1).

Theme 1: Experiences from daily life with polypharmacy

Informants demonstrated different strategies to cope with polypharmacy in everyday life. Some were satisfied with their complete medicine therapy, whereas others found it hard to accept the need for medicines. The informants' trust in their own capacity to handle their medicines varied, and several challenges were revealed. Some experienced having too many pills, which could cause concern and anxiety.

1.1 Experience of overtreatment causes psychological unease

Many informants experienced having too many pills. They were uncertain about how the drug therapy affected their body and found it hard to keep track of medicines from day to day. For some, this feeling was overwhelming and resulted in concern and resignation. Some felt forced to consume medicines, and experienced that their opinion did not matter. One woman described feeling anxious and powerless as she felt forced to take pills prepared for her, and another was afraid she would develop depression from all her medicines and considered quitting altogether.

"One can't refuse, can you? If they have decided that it would be good if you tried this medicine too, then you cannot say "No, I don't want more". (Informant 12; man, 74 years, 30 medicines)

Dissatisfaction with polypharmacy led to increased need for autonomy regarding medicines. One informant reduced the number of pills by discontinuing one medicine at a time without informing her doctor. If there was no symptom relapse, she might not resume the treatment.

"I'm thinking does one really need these pills...I just feel "no". No, I won't take this pill today, I will see tomorrow. That's actually how I do it! It's trial and error for me. Not just one day, it has to be a couple of days because one day is nothing. So I try it out and sometimes I feel better and sometimes worse." (Informant 4; woman, 74 years, 13 medicines)

1.2 Confidence in own capacity

Some informants described how they consciously deviated from the doctor's recommendations regarding medicine dosing, to better fit their daily activities. Several informants trusted their own capacity to handle their medicines and could differentiate between crucial pills and those that could be omitted occasionally.

"I'm very careful, I have two tablets for the heart, or for the breathing and that, or heart failure or what's it called. I'm very careful with those, but the others, if I were to forget some of them one day then I know that that one, the gout, I can do without and that other one I can do without" (Informant 8; woman, 86 years, 14 medicines)

Several informants were aware that discontinuation of medicines may cause disease relapse, which increased their motivation to pursue their drug therapy.

"I have had lithium for many, many years. I was depressed long ago. One doctor terminated that treatment, and it was a disaster. So I will probably eat it for the rest of my life, until I die so to speak" (Informant 14; man, 90 years, 7 medicines)

1.3 Medicines' impact on everyday life

Informants who experienced allergic symptoms, diarrhoea, loss of hair, faecal and urinary incontinence, nausea, dizziness, or fatigue sometimes suspected side-effects. A woman who suffered from diarrhoea as presumed side effect described that her symptoms were not taken seriously by healthcare professionals. Moreover, she experienced social isolation as she did not dare to leave her house.

"I have told them, I mean I do not dare to go out, because several times it just... I had to throw myself in the car and drive home because of the pain. It is like a cramp in the stomach, I felt it, but it just poured down. Shoes and clothes... I was at my son's place for dinner." (Informant 7; woman, 80 years, 10 medicines)

1.4 Individual adaptation to regular intake of medicines

Some informants were sceptic towards medicines whereas others found them easy to accept, but in the end, many informants were thankful for medicines. Once integrated in everyday life, initial doubt or mistrust decreased.

"Without the medicines I wouldn't be here. I believe in my medicines, that it helps and makes me stay the way I am and even become healthier" (Informant 11; woman, 85 years, 9 medicines)

Still, informants stated that living with polypharmacy was an everyday challenge in practical terms. Such challenges could be to remember when to take medicines, to open the packages, to dispense doses, and to administer them correctly. Several informants used a multi-dose medicine dispenser, a "Pill organizer", that they filled themselves or got filled regularly by the HC nurse. Others used the medicine dispensing system "Apodos", a dosing aid with disposable plastic bags containing all pills for one or two weeks' use. Still, several informants regarded it as problematic that they forgot to take their medicines, which commonly occurred with pills that should be taken between meals.

"The worst thing is that if I should take four, one is at mid-day when I don't eat. And that's the one I forget sometimes" (Informant 14; man, 90 years, 7 medicines)

Pill organizers or Apodos were perceived as useful tools. However, the practical handling of plastic bags was challenging, thus counteracting the correct intake of medicines.

"And now with these bags, I cut them open with my injured hand and empty them. Then I sit here and fill my Pill organizer. When that is done, I count. Did I fill in all six? Sometimes, I might have dropped one. This one is washed with chlorine (pointing out a flyswatter), I grab the swat and pick it up from the floor" (Informant 9; woman, 77 years, 6 medicines)

Theme 2: Dependency on the relationship to health care professionals

The informants conveyed a range of experiences from their relations to professionals within the healthcare system. Commitment from healthcare professionals and sincere communication were pointed out as crucial for transfer and reception of knowledge. Some expressed trust and satisfaction, while others had negative experiences of contacts with healthcare professionals which caused frustration and feelings of powerlessness.

2.1 Communication and knowledge are essential to feel safe

Many informants described good communication with their GP. They felt listened to and received useful information. However, in case of poor communication and uncertainty of what had been said, informants found it difficult to participate actively in their own care and treatment. One informant was uncertain of when to take her medicine for angina since she was unsure of the symptoms of angina.

“My GP has given me something else that she wants me to take when I have angina, is that what it’s called? But frankly I don’t know when I have angina, still I take it occasionally.” (Informant 8; woman, 86 years, 14 medicines)

There were also uncertainties regarding the reasons for treatment with some medicines. Indication for each medicine is documented in the patient's medicine list, but still, this information is seldomly phrased in a way that the patient understands. One informant exclaimed:

“...and hypokalemic what is that? Hell knows... what that means”. (Informant 7; woman, 80 years, 10 medicines)

Another informant believed that medicines gave rise to further diseases and was afraid of a vicious circle.

“Yes, they could spend more time looking into the fact that one eats too many medicines. I mean, it’s not good for the body either. And there will be another disease added on when you get that medicine. Another disease will come. And when it goes on, there will be no improvement. It just gives rise to yet another” (Informant 4; woman, 74 years, 13 medicines)

2.2 The value of continuity

Several informants were satisfied with the continuity of care and expressed genuine trust in their GPs and the HC nurses, who some of them had known for years. They reported that the quality of the interaction with healthcare professionals in many ways was dependent on the personal contact and if you had had the chance to get acquainted. Moreover, the attitude towards certain medicines was influenced by the relationship to the prescribing physician.

"I would never do that (stop taking medicines without telling the doctor). No. If you only do what he tells you to, everything will be fine." (Informant 3; woman, 81 years, 11 medicines)

Some informants who had received medical care and prescriptions from several physicians were concerned and uncertain, especially when physicians in both primary and secondary care had made alterations of their prescriptions. One informant felt as if she had one specialist for each organ, but no one who had the overall responsibility for her medicines.

"I had medicines for something that I didn't need and since many doctors were involved it became confusing, that's how I experienced it" (Informant 6; woman, 90 years, 15 medicines)

In several cases, informants expressed trust in the HC nurses, who coordinated care and with whom they could discuss medicine-related issues. Some experienced better continuity with nurses than with physicians, and the cordial relationship with the HC nurse was highly esteemed.

"I have the nurse who is my... my friend. She likes to come herself to give the medicines. Every 14th day they do it for me, I don't know how to do it since I cannot see". (Informant 8; woman, 86 years, 14 medicines)

2.3 Building trust or feeling disregarded by the GP

Several informants requested increased commitment from their GP in terms of active listening. One participant described an appointment with a GP like this:

"When I was at my appointment, the doctor stared into that computer screen while talking to me. (...) I have heard so many who get irritated with the physicians, they just sit and glow at the screen." (Informant 6; woman, 90 years, 15 medicines)

Another informant felt overridden when the GP had not paid attention to what she regarded as the main problem.

"She did not care what I had come there for, my knee, but it was all about the diabetes. I was a little mad at her and said I wanted to change doctor, because she did not really listen." (Informant 3; woman, 81 years, 11 medicines)

Informants who experienced absence of effect or side effects of their drug therapy expressed that this was dismissed by the GP who attributed the symptoms to the process of natural ageing.

“The doctor knows medicine, naturally, but the patient is the one with the best knowledge of his body. It was like they believed in the test results, the blood samples, more than in me, my body.” (Informant 2; man, 88 years, 13 medicines).

2.4 Experiencing poor access to healthcare

Some informants experienced that over the years, it had become more and more difficult to get in touch with their GP. This raised feelings of mistrust and ambivalence. When they finally got in contact and had obtained an appointment, consultation time was too short for questions or discussion.

“Earlier on you got invitations to appointments one or twice a year. Now you must demand to be let in. And I must call and ask for my prescriptions when they have run out. You ought to have knowledge about everything and thank God I still have a clear mind.” (Informant 2; man, 88 years, 13 medicines)

One informant expressed empathy with the GPs because of the heavy workload that hampers continuity.

“It can’t be easy to be a doctor nowadays in primary health care. They are obliged to see an awful lot of patients; they never have time to get emotionally involved. I wouldn’t want to be a doctor and work under those circumstances, as they do here. I understand them though, they don’t have time to sit with me and go through pills” (Informant 6; woman, 90 years, 15 medicines)

Discussion

Summary

The aim of this study was to gain understanding of how patients in HC experience polypharmacy in daily life. Our first main finding is the considerable variation in experiences from living with polypharmacy. For some patients, multiple medicines had become part of their daily routine and was not perceived as problematic, whereas for others, it was associated with great unease. The individual differences point to the second main finding which is the importance of sincere communication in the patient-GP relationship in order for these patients to feel safe regarding drug therapy. The third main finding is that informants in our study experienced improved continuity with the healthcare unit through regular contact with HC nurses, who were regarded as a significant support and had a coordinating role working as a bridge to the GP. Several informants experienced a more casual relation with the HC nurse than with the GP, which could entail an underutilized opportunity for discussions about medicine-related experiences and points to the value of interprofessional teamwork.

Strengths and limitations

To the best of our knowledge, this is the first study to qualitatively explore experiences from polypharmacy in daily life in a HC population as well as how these patients perceive contacts with healthcare professionals. It is a strength that interviews were carried out with these multimorbid and frail older persons in their homes, as we believe that this context facilitated for the informants to feel secure and speak freely. The gender distribution with 11 women and 6 men corresponds to the distribution in the whole HC population in Stockholm and even in the Nordic countries (20), which enhances transferability of findings. However, transferability is reduced by the fact that no patients with dementia were included, as this diagnosis is common in the HC population. Therefore, our research team plans to complement with a study that includes patients with dementia through interviews with relatives. The fact that interviews were conducted by four interviewers could be a limitation, however, this was handled through a shared interview guide as well as close cooperation within our multi-professional team through the analysis. We believe that the team members' different experiences and competences from the medical, psychological, and sociological field have contributed constructively to reflexivity and the interpretation of data. The trustworthiness of our findings is strengthened by use of multiple researchers engaged in each of the analytical phases.

Comparison with existing literature

A considerable variation regarding experiences of polypharmacy was identified. This is in line with findings in a systematic review of qualitative studies from 2020 (21), highlighting the importance for healthcare professionals to actively solicit individual patients' perspectives on drug therapy to facilitate shared decision-making. Informants in the current study presented different reasons for deviating from recommendations regarding medicine dosing. Regardless of the cause, these patients need to be offered support from the GP to make informed choices about their medicines. This is reflected by findings from a British study suggesting that healthcare professionals should guide patients to 'get to know' their medicines and how to administer them to improve health outcomes safely (22). However, due to negative experiences with physicians regarding the ability to discuss concerns about medicines, previous findings show that patients tend to seek alternative sources of information that may, in the end, imply medical risks (23). In this context, our finding that patients may not dare to question physicians about medicines appears as a great concern that must be addressed.

Findings regarding communication and continuity of care are in line with previous research in the older population. Several studies from Sweden and other European countries have identified the patient-GP relationship as central for multi-diseased older patients' views on medicines, still, these studies did not include HC patients as a specific group (24, 25). Most informants in our study trusted their GPs, but nevertheless some felt unable to communicate concerns regarding medicines. Thus, more than trust seems to be required for HC patients to participate in their own treatment and to feel safe in the patient-GP relationship. A study from

Denmark suggests that blind trust in the GP may prevent patients from asking questions and discuss medical decisions, and that power imbalances and lack of continuity of care may be more important to address (26). A relationship characterized by trust, but also healthy questioning and open communication seems to enhance older persons' participation in their own healthcare (27).

Regarding interprofessional teamwork, nurse-led interventions have shown to improve medicine adherence among home-dwelling older adults newly discharged from hospital care (28). Several studies point to the value of nurses for pharmacovigilance, particularly for identifying adverse drug reactions (29, 30). However, to achieve an improved identification of potential obstacles and risks it is suggested that nurses' specific knowledge on the topic should be advanced through in-service training and education (31), and that awareness of this matter should be improved among healthcare students (32).

Implications for practice

Our results show that older persons were not always encouraged or invited to shared decision-making by the GP, even if they showed interest in medicine-related issues. Still, a large proportion of older persons wish to be actively involved in their drug therapy, which has been described as a potential resource to enhance patient safety (33). Also, shared decision-making has been associated with improved health outcomes (34). Person-centred care has emerged as an area of growing interest in the last decade (35), but it remains to be clarified how a person-centred approach should be implemented for frail HC patients (36).

Additional information

Funding

Health Research Fund, Region Stockholm (ALF grant nr 20200202). Network healthcare (NSV), Region Stockholm (grant nr FoUI-937161). Swedish order of Freemasons. Research Fund for Rehabilitation and medical Research. Karolinska Institutet Foundations and Fund (grant nr 2020-01803).

Ethical approval

The study design was approved by the Regional Ethics Committee at Karolinska Institutet in Stockholm, Sweden, Dnr 2018/1595-31/5.

Competing interests

The authors declare no competing interests.

Acknowledgements

The authors would like to thank the staff at the primary healthcare practices who helped to find informants for this study. The authors also greatly thank all patients for participating in the study.

References

1. National Board of Health and Welfare. National indicators for the quality of drug therapy in elderly persons [Indikatorer för god läkemedelsterapi hos äldre]. Stockholm.2017.
2. Wastesson JW, Cedazo Minguez A, Fastbom J, Maioli S, Johnell K. The composition of polypharmacy: A register-based study of Swedes aged 75 years and older. *PLoS One*. 2018;13(3):e0194892.
3. Gallagher P, Barry P, O'Mahony D. Inappropriate prescribing in the elderly. *J Clin Pharm Ther*. 2007;32(2):113-21.
4. Midão L, Giardini A, Menditto E, Kardas P, Costa E. Polypharmacy prevalence among older adults based on the survey of health, ageing and retirement in Europe. *Arch Gerontol Geriatr*. 2018;78:213-20.
5. Bagge M, Tordoff J, Norris P, Heydon S. Older people's attitudes towards their regular medicines. *J Prim Health Care*. 2013;5(3):234-42.
6. Tordoff J, Simonsen K, Thomson WM, Norris PT. "It's just routine." A qualitative study of medicine-taking amongst older people in New Zealand. *Pharm World Sci*. 2010;32(2):154-61.
7. Bokhof B, Junius-Walker U. Reducing Polypharmacy from the Perspectives of General Practitioners and Older Patients: A Synthesis of Qualitative Studies. *Drugs Aging*. 2016;33(4):249-66.
8. Pound P, Britten N, Morgan M, Yardley L, Pope C, Daker-White G, et al. Resisting medicines: a synthesis of qualitative studies of medicine taking. *Soc Sci Med*. 2005;61.
9. Schopf AC, von Hirschhausen M, Farin E, Maun A. Elderly patients' and GPs' perspectives of patient-GP communication concerning polypharmacy: a qualitative interview study. *Prim Health Care Res Dev*. 2018;19(4):355-64.
10. Oliveira LP, Santos SM. [An integrative review of drug utilization by the elderly in primary health care]. *Rev Esc Enferm USP*. 2016;50(1):167-79.
11. Genet N, Boerma WGW, Kringos DS, Bouman A, Francke AL, Fagerström C, et al. Home care in Europe: a systematic literature review. *BMC Health Serv Res*. 2011;11(1):207.
12. Anell A. The public-private pendulum--patient choice and equity in Sweden. *N Engl J Med*. 2015;372(1):1-4.
13. Modin S, Furhoff AK. The medical care of patients with primary care home nursing is complex and influenced by non-medical factors: a comprehensive retrospective study from a suburban area in Sweden. *BMC Health Serv Res*. 2004;4(1):22.
14. Modin S, Furhoff AK. Care by general practitioners and district nurses of patients receiving home nursing: a study from suburban Stockholm. *Scand J Prim Health Care*. 2002;20(4):208-12.
15. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*. 2006;3(2):77-101.

16. Kvale S. Den kvalitativa forskningsintervjun. 3. [rev.] uppl. ed. Brinkmann S, editor. Lund: Studentlitteratur; 2014.
17. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349-57.
18. Saunders B, Sim J, Kingstone T, Baker S, Waterfield J, Bartlam B, et al. Saturation in qualitative research: exploring its conceptualization and operationalization. *Quality & quantity*. 2018;52(4):1893-907.
19. Sandelowski M. When a cigar is not just a cigar: alternative takes on data and data analysis. *Res Nurs Health*. 2011;34(4):342-52.
20. Ronneikko JK, Jamsen ER, Makela M, Finne-Soveri H, Valvanne JN. Reasons for home care clients' unplanned Hospital admissions and their associations with patient characteristics. *Arch Gerontol Geriatr*. 2018;78:114-26.
21. Eriksen CU, Kyriakidis S, Christensen LD, Jacobsen R, Laursen J, Christensen MB, et al. Medication-related experiences of patients with polypharmacy: a systematic review of qualitative studies. *BMJ Open*. 2020;10(9):e036158.
22. Rathbone AP, Todd A, Jamie K, Bonam M, Banks L, Husband AK. A systematic review and thematic synthesis of patients' experience of medicines adherence. *Res Social Adm Pharm*. 2017;13(3):403-39.
23. Krska J, Morecroft CW, Poole H, Rowe PH. Issues potentially affecting quality of life arising from long-term medicines use: a qualitative study. *Int J Clin Pharm*. 2013;35(6):1161-9.
24. Moen J, Bohm A, Tillenius T, Antonov K, Nilsson JL, Ring L. "I don't know how many of these [medicines] are necessary.." - a focus group study among elderly users of multiple medicines. *Patient Educ Couns*. 2009;74(2):135-41.
25. Clyne B, Cooper JA, Boland F, Hughes CM, Fahey T, Smith SM. Beliefs about prescribed medication among older patients with polypharmacy: a mixed methods study in primary care. *Br J Gen Pract*. 2017;67(660):e507-e18.
26. Schiøtz ML, Frølich A, Jensen AK, Reuther L, Perrild H, Petersen TS, et al. Polypharmacy and medication deprescribing: A survey among multimorbid older adults in Denmark. *Pharmacology research & perspectives*. 2018;6(6):e00431.
27. Meranius MS, Hammar LM. How does the healthcare system affect medication self-management among older adults with multimorbidity? *Scand J Caring Sci*. 2016;30(1):91-8.
28. Verloo H, Chiolo A, Kiszio B, Kampel T, Santschi V. Nurse interventions to improve medication adherence among discharged older adults: a systematic review. *Age Ageing*. 2017;46(5):747-54.
29. Johansson-Pajala RM, Jorsäter Blomgren K, Bastholm-Rahmner P, Fastbom J, Martin L. Nurses in municipal care of the elderly act as pharmacovigilant intermediaries: a qualitative study of medication management. *Scand J Prim Health Care*. 2016;34(1):37-45.
30. Bigi C, Bocci G. The key role of clinical and community health nurses in pharmacovigilance. *Eur J Clin Pharmacol*. 2017;73(11):1379-87.
31. Salehi T, Seyedfatemi N, Mirzaee MS, Maleki M, Mardani A. Nurses' Knowledge, Attitudes, and Practice in Relation to Pharmacovigilance and Adverse Drug Reaction Reporting: A Systematic Review. *BioMed research international*. 2021;2021:6630404.
32. Reurman M, Tichelaar J, Piersma B, Richir MC, van Agtmael MA. Urgent need to modernize pharmacovigilance education in healthcare curricula: review of the literature. *Eur J Clin Pharmacol*. 2018;74(10):1235-48.
33. Holmqvist M, Thor J, Ros A, Johansson L. Older persons' experiences regarding evaluation of their medication treatment-An interview study in Sweden. *Health Expect*. 2019;22(6):1294-303.
34. Stacey D, Hill S, McCaffery K, Boland L, Lewis KB, Horvat L. Shared Decision Making Interventions: Theoretical and Empirical Evidence with Implications for Health Literacy. *Stud Health Technol Inform*. 2017;240:263-83.

35. Sharma T, Bamford M, Dodman D. Person-centred care: an overview of reviews. *Contemp Nurse*. 2015;51(2-3):107-20.
36. Kogan AC, Wilber K, Mosqueda L. Person-Centered Care for Older Adults with Chronic Conditions and Functional Impairment: A Systematic Literature Review. *J Am Geriatr Soc*. 2016;64(1):e1-7.

Tables and figures

Box 1. Home care in Swedish primary healthcare

Home care systems differ between countries in Europe (11). The Swedish home care (HC) system, operated by nurses and physicians from local primary healthcare centres (12), is intended for frail and multimorbid older adults with considerable need for primary healthcare and difficulties to visit GP practices. These patients commonly have both medical and functional problems (13). In Sweden, a patient will be registered as HC patient if a district nurse's assistance is required $\geq$ twice/month. Regular visits of a district nurse enable for older multi-diseased people with reduced functional capacity and/or cognitive impairment to receive care in their familiar context and maintain their independence. This close contact may also diminish the need for visits by the GP (14). In 2019, 19.000 persons in Region Stockholm received HC. The typical Swedish HC patient is 82 years old, has four chronic diseases and is treated with 13 different medicines. These patients are often granted support from the municipal HC services, who offer daily assistance to enable older persons to live at home. When functional decline worsens, HC patients may need nursing home care.

Figure 1: Themes 1 and 2 are presented in banners, with categories below