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This is the accepted version of a paper published in *Scandinavian Journal of Caring Sciences*. This paper has been peer-reviewed but does not include the final publisher proof-corrections or journal pagination.

Citation for the original published paper (version of record):

Craftman, Å., Westerbotn, M., von Strauss, E., Hillerås, P., Marmstål Hammar, L. (2015)
Older people's experience of utilisation and administration of medicines in a health- and social care context.

Scandinavian Journal of Caring Sciences

<http://dx.doi.org/10.1111/scs.12207>

Access to the published version may require subscription.

N.B. When citing this work, cite the original published paper.

This is the peer reviewed version of the following article: Gransjön Craftman, Å., Westerbotn, M., von Strauss, E., Hillerås, P., & Marmstål Hammar, L. (2015). Older people's experience of utilisation and administration of medicines in a health- and social care context. *Scandinavian Journal of Caring Sciences*. Advance online publication. which has been published in final form at doi: 10.1111/scs.12207. This article may be used for noncommercial purposes in accordance With Wiley Terms and Conditions for self-archiving.

Permanent link to this version:

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Older people's experience of utilization and administration of medicines in a health- and social care context

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Acknowledgements

First and foremost, the authors would like to thank all the participants in this study. We gratefully acknowledge financial support from Sophiahemmet University, The Sophiahemmet Foundation for Clinical Research and King Gustaf V and Queen Victoria's Freemasons Foundation.

Contributions

Study design: Åsa Gransjön Craftman, Margareta Westerbotn, Eva von Strauss; data collection: Åsa Gransjön Craftman, data analysis: Åsa Gransjön Craftman, Lena Marmstål Hammar, Margareta Westerbotn, and manuscript preparation: Åsa Gransjön Craftman, Margareta Westerbotn Lena, Eva von Strauss, Pernilla Hillerås, Marmstål Hammar.

Funding

The study was financed by a grant from The Sophiahemmet Foundation for Clinical Research and King Gustaf V and Queen Victoria's Freemasons Foundation and supported by Sophiahemmet University College, Stockholm.

Ethical Approval

Approval for the study was granted by The Regional Ethical Review Board in Stockholm, registration numbers: 2009/583-31/5 and 2011/1154-32.

Key Words

Older people, assistance, medicine use, social care, medicine administration at home.

Introduction

It is well recognized that the overall population is ageing. Longer life expectancies have led to a demographic change that is expected to continue and pose challenges worldwide (1). To meet future health care needs, nursing and caring activities directed towards chronically ill older people are likely to be increasingly performed in patients' own homes (2, 3). Home is a personal space and care providers may have a disturbing impact on the patients' perceptions of well-being, as a result of being dependent on others (4).

Background

Multimorbidity affects more than half of the elderly population and is suggested to relate to a long exposure and increased vulnerability to risk factors for chronic health problems (5). A strong association of multimorbidity, defined as the coexistence of more than two chronic diseases in the same individual, is well recognized with age (6). The use of prescription medication and the increase of mean number of drugs being used will continue to grow in relation to an increasing demand for medications available to treat chronic ageing related diseases (7-9). The situation becomes more complex when medication administration has become a mutual question for health and social care. It has also become a remit of "unqualified" Home Care Assistants (HCAs) when an increasing number of people are dependent on multiple medications and choose to live at home, requiring a range of levels of assistance (10). Failure to adhere to prescribed regimens may lead to deterioration of medical conditions, readmission to hospital, and adverse effects or reactions (11).

Physical, visual and cognitive abilities may hinder practical aspects like recognizing packaging and reading enclosed instructions of medication regimen (12). The physician is responsible for assessing the person's ability to manage self-administration of medication in

the prescribed manner. If this ability is lacking, assistants should be provided to support and improve adherence to the regimen (13). Factors that may influence medicine adherence negatively have been identified as age, physical and mental condition, living alone and chronic diseases. A significant number of older people living at home experience problems related to their medication e.g. adverse side effects, but do not recognise or identify the issues resulting in lack of communication to district nurses or physicians (11, 14). To deliver health care and social care to older people living at home in need of assistance with administration of medication, delegation between personnel is practiced in a number of countries (15). Primary health care nurses often have authority to delegate the administration of medicine to home care assistants (HCA). HCAs in the Swedish context of municipal social care do not possess formal knowledge in this regard. Permission to administer medicines should only be given to HCAs with appropriate training and assessed knowledge to administer medicines. The delegation is made across boundaries of health and social care (16, 17), and the resulting quality of delegation influences patient safety (18). The authorities responsible for health and social care aim to offer support to community-dwelling elders in order to allow them to remain in ordinary housing, despite significant frailty and a need for social and health care (19-21). Breitholtz, Snellman and Fagerberg, (22) described how older people adapt to their new situation and maintain a perception of themselves as being independent. Thus they organize their homes to maintain independence with support from the caregivers. HCAs' organization, however, is not perceived as having been structured according to older people's needs. This creates dependency in older people and heightened awareness of limitations that require HCAs' assistance. Moreover, Hammarström and Torres (23) found that this situation resulted in a negative emotional outcome, described as feelings of powerlessness, a perception of negative dependence and loss of self-determination.

Caring should always be person-centred which involves shared decision-making. This means that persons are able to confirm their position in the social world, in relation to place and self. The care becomes individualised and can increase well-being and independence of the older person (24, 25). When planning, organising, and providing care older peoples' perceptions and experiences of being cared for at home provide essential information. The aim of this study was to describe how older people with chronic diseases, living at home, experience the use and assistans of administration of medicines in the context of social care.

Method

Participants

Inclusion criteria for this study were: being older than 65 years of age; being able to speak, read and understand the country's native language; being cognitively able and competent; living in own home; requiring assistance with administration of medicines from an HCA in the context of social care. Five of the participants were identified from the database of the Swedish National study on Aging and Care on Kungsholmen (SNAC-K), a longitudinal population-based study of people over 60 years old, living in central Stockholm. The design of the study has been described elsewhere (26). In compliance with case sampling methodology, the authors sought variation and quality of data (27); therefore, five participants were identified through academic health care centres in a suburban area in a rural county in Sweden. The administrator for the SNAC-K database (a registered nurse) and the recruited district nurses from the academic health care centre were informed about the study, both verbally and in writing.

Six women and four men were included in the study. The participants had a variety of morbidities including previous stroke, cardiac disease, diabetes, Parkinson's disease, age-related

reduction of mobility and undiagnosed altered cognition, which entitled them to assistance with administration of medicines and social care provided by HCAs. All participants lived alone and were aged 68 to 94 years, with the mean age of 84, and were assisted by different social care units.

Data collection

Qualitative interviews were conducted for the purpose of gaining an understanding of older people's experiences of administration of medicines. The first author conducted the audio-recorded interviews in the homes of the participants. The interviews started with the question: "Could you please tell me about your experience of receiving assistance with your administration of medicines?" Probing questions were asked to clarify and confirm how the answers were being understood. The interviews lasted between 20 and 60 minutes and were transcribed verbatim.

Ethical considerations

The study was carried out in accordance with Ethical Guidelines for Nursing Research in the Nordic Countries (28). Approval for the study was granted by The Regional Ethical Review Board in Stockholm, registration numbers: 2009/583-31/5 and 2011/1154-32. Participants were informed in writing and verbally about the study, the voluntary nature of their participation and their right to withdraw at any time without consequences. Moreover, that confidentiality would be protected and that any quotes from the interviews would be formulated as to provide anonymity. Written consent was obtained from all participants.

Data analysis

The latent analysis followed procedures described by Graneheim and Lundman (29) and began by reading the interview text several times to obtain an overall sense of the content as a whole. Textual content related to the study aim was marked and subsequently copied to a separate document. After this, the texts were broken down into meaning units, which consisted of words, sentences or phrases relating to the aim of the study. In the next step the meaning units were abstracted and labelled with codes. Codes could be discrete objects, events or other phenomena and were understood in relation to the context. As a third step, codes were continuously compared to identify differences and similarities. Based on the codes, categories were developed which denoted expressions of the manifest content of the text. The fourth step was to compare and critically analyse the categories to determine the underlying meaning. Three secondary themes were developed which became a consistent motif, or guiding principle (“red thread”) throughout the condensed meaning units, codes and sub themes on an interpretative level, and expressed the latent content of the text. The theme, *Balancing empowerment and dependence* links those themes together. An example of the analysis process is shown in table 1.

(Insert table 1 about here)

Findings

The findings are presented through the theme, *Balancing empowerment and dependence* and three sub-themes, *Health in transition leading to dependence*, *Balancing intrusion and respect for personal integrity and space* and *Moving between trust, mistrust and control*, to describe how older people with chronic conditions living at home experience the use of medicine and administration in the context of social care.

Balancing empowerment and dependence

Health in transition leading to dependence

The participants reflected on their life story and how age and episodes with illness or trauma had changed their life situation, including the need for assistance with daily activities and medicine regimens. The high number of medicines was related to age and different ailments that require an assortment of prescribed medicines to be administered in various ways, e.g. inhaler, pills and eye drops at different times during the day. Some participants voiced acceptance of the medicine regimen in general because of their prevailing health situation, and regarded the physician's knowledge as superior. Others found it important to know the purpose of the medicine regimen because of the number of medicines. One participant stated that it was important to know the cause and purpose to be able to avoid feeling sleepy or sedated.

"I have many types of medication and I need to know what they are for and where they are stored" (P.3)

The participants pointed out that physical performance declines with age to varying degrees, and this had resulted in shortcomings in their ability to self-manage their medication, as well as in the necessary prerequisites for carrying out such activities in daily life. Physical limitations in this context were expressed as natural and something they accepted in life, e.g. difficulties encountered when opening a pillbox. The assistance was described as reflecting their age-related shortcomings, e.g. poor health and memory loss; this potentially creates stress in receiving assistance. An example was given by two participants who described how they tried unsuccessfully to manage their medication and stated that this was no longer something they should be doing. As a participant made the following comment:

"I don't remember, but it was wrong, not life threatening [medicine], but something, it's not my business [to manage medicines]" (P.5)

It could also be difficult to stay abreast of new information on the medicines and why they were prescribed due to the number of different medications.

“If I knew why I took them, I would know a lot. I take so many different medicines so I myself have turned into poison” (P.7)

A loss of skills related to age and chronic conditions was balanced with the help of assistants from social care. Some participants voiced the opinion that life had become easier and more convenient once the HCAs handled the administration of medicines. Responsibility was now in someone else’s hands in a natural way. Moreover, some suggested that HCAs were seen as providing a more comprehensive relationship when they also performed administration of medicines and not only social care assistance; this added a meaningful dimension to the care relationship.

“It is a good thing to not be responsible [for the administration of medicine]...and I think you get a little, a little you know, closer when they not only take care of the household” (P.10)

None of the participants found it realistic to expect the same support from relatives, so social care and HCAs constituted the only option for administration of medicines.

Balancing intrusion and respect for personal integrity and space

Some participants described vagueness in decision-making when they were provided with assistance in administering medicine. Few of the participants were involved in the decision to receive assistance with administration of medicine or even in raising the topic; neither could

they remember being asked for their consent. The commencement of receiving assistance with the administration of medicine was described to be related to a discharge from hospital, or something which slowly had been integrated in the wholeness of the social and medicine context. A general theory was that it probably was a physician, a nurse or an HCA who made the decision on behalf of the participant. However, it was stated that given the prerequisites for receiving help, this is how it must be. One participant expressed medicine assistance as something one involuntarily accepts.

“I have a feeling that they think it is their job [home care assistants]... they seem to have gotten such instructions...it just became this way” (P.7)

“I do not know for sure who arranged it, maybe it was the physician? It is nothing they have discussed with me anyway.” (P.6)

Some participants explained how they strived to balance the intrusion into their personal space by identifying strategies that meant the assistants adapted to their terms. They created a situation in which administration of medicines became a partnership. One example was to unlock and lock the medicine cabinet for the HCAs.

Similarly, the HCA could be asked to place the dosage from the pill dispenser in an eggcup. This made it possible for participants to take the medication when it suited them, e.g. at bedtime, thus not needing to adjust to the HCA's schedule. This was one way to balance empowerment and self-determination with the need for help from assistants and others. The participants made the point that they had become used to assistance from social home care but that this dependence was something one needed to adjust to. Formalities such as using the pill

dispenser and signing lists after administering a dosage were described as important elements in the administration, ensuring that everything was done correctly. One participant expressed displeasure with changes in the home environment. The kitchen table where she used to sit and solve her crossword puzzle had been transformed by the HCAs into a medicine cupboard with medicine records and pill dispenser, which intruded upon her daily life and routines.

Participants commented on how they had needed to adjust their schedules to those of the HCAs' work schedules. Participants also reported making their own decisions, e.g. to take more paracetamol than their physicians had prescribed or to use naturopathic substances a friend recommended. It was also a good and safe thing to know how to inhale if the HCA was delayed, according to those interviewed. Furthermore, the HCAs could be asked to set out medicines from original packing even if this was not allowed by the rules and some pills could be excluded.

Moving between trust, mistrust and control

Different degrees of trust were voiced in relation to the chain of professions in the medical context. The district nurse was regarded as a guarantee for correct administration of medicines. Participants expressed their trust that the district nurse or physician had complete control over their medicine regimen.

"It is a true old school nurse who takes care of the pill dispenser, not a little girl" (P.1)

Physicians were perceived positively and as trustworthy; participants were comfortable with the prescribed medicine regimen and did not question it. According to those interviewed, the physicians are aware of which medicines are appropriate together. This was considered important when one was taking multiple medicines. The physician knows best and the

participants expressed the opinion that one should “stick with the same doctor”. The district nurse made sure the pill organiser was set with the prescribed medicines, and made arrangements in the event of alterations.

The participants voiced a feeling of trust and safety when the relationship they had with the HCA was perceived to be well-functioning. The HCAs’ medical knowledge was not the most important point to some participants. Their workload was heavy enough in relation to performing social care. Medical tasks were, therefore, not something they were expected to be fully responsible for. It was assumed that they had the necessary skills to perform the administration in a practical way, but were not knowledgeable about the purpose or side effects. However, one participant who was a retired nurse found it difficult to cope with the HCAs’ lack of knowledge, but did not want to correct them either. Trust and safety was also related to the participants’ perception of the HCAs’ workload. In general, the participants found them to be overloaded with work and thought they made the best of the situation. In some cases, HCAs were described as showing a low interest in their job and as having a high stress level, which was perceived negatively. This was something that influenced the situation and relationship with the HCAs; it was a source of empathy for them and led to care recipients trying to lighten their carers’ load.

“Sometimes they are so overloaded with work, so they cannot pay me a visit [administer medicines], instead they call me...I have said they must call me if they aren’t coming [to remind me about the medicine]” (P.3)

According to the participants, most of the HCAs were educated assistant nurses but lacked medical skills. They stated that you should and must trust them since there are no other options.

The participants found it important that the HCAs should first and foremost adhere rigorously to their work routines, because sometimes they forgot to administer a dose. Participants who found it important to maintain control of their medicines expressed this as a way to uphold the medicine regimen. If a substitute filled in, or the regular HCA seemed uncertain about what to do, it was better to take care of the administration of medicines yourself. Trust in the assistance situation fluctuated among participants due to many HCAs administering medicines and time to get used to different routines. Although participants expressed a belief that they were being cared for by the HCAs to the best of their ability, however both trust and mistrust was expressed in relation to HCAs' skills and knowledge in the context of administration of medicines.

Although they generally felt that administration of medicine functioned well practically, they were aware of the different levels of medical knowledge among the HCAs. The participants expressed patience with HCAs who seemed uncertain, and sought outside advice if something was unclear about their medicine. According to participants it was important to be aware of what medicines one should be receiving because of the risk of mistakes when an unfamiliar HCA came to administer dosages.

"...I feel safe with those who assist me now. I don't know what will happen if they leave..." (P.4)

Participants expressed doubt as to whether HCAs were able to recognize when contacting a medical professional is necessary. Some felt that of course the HCAs should have knowledge of medical topics when they were allowed to perform administration of medicines. Even if they do not have a formal education you must have trust in the HCAs and accept their decision, but remain alert. One participant gave an example of having been given an incorrect insulin injection on two occasions. This is acceptable as long as you are clear-headed and conscious of your health. Most participants wanted to see for themselves that the medicines were correct.

Another described the perception like this;

“Of course I feel safer if they know what is right and wrong. The personnel in the day time are the most educated ones in contrast to those who come in the evening” (P.8)

Participants also expressed a negative perception of the lack of language skills among some staff and insufficient education in elderly care also contributed to a lack of trust. Given these factors, the participants felt they needed to have their medication under control.

Discussion

Reflections on the findings

The aim of this study was to describe how older people with chronic diseases living at home experience use of medicine and administration in the context of social care. This study showed how adjustments were made in everyday life to facilitate transition from independence to reliance upon a care provider, in the context of requiring assistance with medication.

Medication regimens and the need for assistance in the administration of medicines reflected age-related shortcomings and represented a new phase of life. The participants submitted to the change in order to benefit from the help received. Ohman, Soderberg (30) found that chronic disease forces a person to find new ways to accommodate the situation within their life.

Moreover, Ellefsen (31) found self-image important when adjusting to a life of dependence.

In our study the participants expressed their self-image related to the need for medication and their dependence on assistance in relation to the inevitable consequences of chronic diseases and ageing. At the same time, their stories present a pattern of adapting to the life and role changes similar to those described in earlier research (32, 33). Management of changes in personal perceptions relating to receiving assistance with medicine regimen can manifest themselves in active or passive terms. A passive part means adapting, which involves

deferring to health care providers and relinquishing valued territory, while the active alternative is to collaborate with health care providers and strive to maintain a valued role (32). In the present study the administration of medication had become manifest as active by carrying out self-care in collaboration with the HCAs, e.g. by unlocking the medicine cabinet. This was a path to bolster participants' roles as independent persons, thereby preserving their valued self-efficacy. Similar findings are also discussed in previous studies (22, 30) who state that this self-efficacy provides a feeling of control in everyday living, and eases the sense of dependence on others. The desire to make one's own decisions and control one's life is inherent in human nature. McCormack (25) highlights the importance for caregivers to understand what each person values about their life and how they make sense of changes. Westerbotn, Fahlstrom (34) noted mixed reactions regarding assistance with medicine among older people managing medications on their own. They identified distrust in medical services and a feeling of being a burden, yet also a feeling of being deserted when assistance was not available or when it was perceived as inaccessible. Even though participants in our study expressed satisfaction with the help they received to administrate medications, they perceived themselves as not being actively engaged in decision making concerning assistance. To handle their medicines by themselves was seen as something which had been shifted outside their area of knowledge; therefore it became a passive interaction. Bolster and Manias (35) found that registered nurses missed or did not create opportunities to involve the person in the interaction of medication activities. Decision-making was dominated by nurses and activities were largely centred on their understanding of what was important for the person. In this study, the trust in physicians' and district nurses' professional knowledge made the participants' own knowledge of the medicine secondary. Previous research (34, 36) have also showed that knowledge about or the purpose of medication regimens was less important to older people. In our study the HCAs lack knowledge of the medicine regimens and their

results which makes it difficult to identify side effects. The participants' collaboration with the HCAs constituted a safety precaution and especially when substitutes worked or HCAs seemed uncertain, the participants preferred to administer their own medicines. McCormack (25) highlights the importance of the relationship in the sense that person-centred care is based on the caregiver's awareness of the person's social context, care plan and specific needs. In this regard, this study shows how the organisation of medicine and social care leads to contradictions; older people must accept the need for assistance with administration of medicines, but at the same time they must be prepared to reclaim the task whenever needed. When discussing what is desirable and expected of an HCA, participants expressed the view that it should be implicit in the role that anyone who administers medicines should be properly prepared for the task. However, they concluded that this was not always the case. The findings in Craftman, von Strauss (37) study showed that district nurses encountered difficulties in assessing HCAs' skills, but their own work constraints left them no choice other than to delegate this task to them. In the present study, the HCAs' competence requirement in this area was placed in relation to their job situation. They were perceived as overloaded with work and should not have an increased burden of more knowledge requests. Bradford (10) argues that the individual finds it more important that the administration of medication is done safely than who does it. Some participants in this study were annoyed since the HCAs' work overload was perceived to affect the care they received, while others expressed sympathy and adjusted to be supportive. According to a participant, one way to facilitate the HCAs' workload was to let them skip a personal visit for administration of medicines and replace this with a telephone call by the HCA as a reminder. In this situation older people must balance their own needs and safety in relation to the personnel situation of the social care organisation. Similar limitations in assistance were also identified in a study by Ellefsen (31), when HCAs communicated their heavy workload in both verbal and nonverbal signs, e.g.

looking at the watch. According to Hvalvik and Dale (38), older people in the initial phase of a transition process were especially sensitive to RNs' attitudes, and were eager to please them if they perceived that a nurse was busy. This could lead to feelings of being a burden, or avoiding attempts to perform self-care tasks independently. Breitholtz, Snellman and Fagerberg (22) found that caregivers who are stressed, might not see the older people as individual persons, which is not in alignment with person centred care. Being dependent on caregivers' help to manage everyday life challenges the image of self-determination and is stressful.

Methodological considerations

This is a qualitative study, and our aim was to generate new understandings that are comprehensive and logical, and results which might be relevant and transferable to older people in a similar situation. According to Graneheim and Lundman (29) trustworthiness rests upon dependability, and when data collection extends over time this can result in an inconsistency in the collection. In this study, the same person performed all the interviews and the prerequisites for the participants and the research area were consistent over the elapsed time. Our study, nonetheless, contributes new knowledge to the field. We sought to generate insight into older people's experiences of receiving assistance with medicine in the context of social care. The first author conducted the first analyses. To increase trustworthiness three (ÅC, MW, LMH) authors were thereafter involved in the analysis process. Eventual disagreement e.g. with regard to labelling, was discussed by the authors until consensus was reached.

Conclusion

The findings in this present study have illuminated how older people with chronic diseases living at home experience use of medicine and administration in the context of social care. The

findings revealed the complexity of ageing and poor health which requires assistance with administration of medicines in excess of different forms of assistance is required. Presently social care is applied as a solution for delivering assistance in administering medicines for persons living alone. Through practical help, assistance from social care with the administration of medicines can lead to better compliance with a medication regimen and make daily life easier. However, the situation is multifaceted; dependency upon assistance from social care affects self-efficacy, and the need to balance personal empowerment against a need for assistance and a skeptical perception of the HCAs' knowledge of medication and patient safety. However, trust in the physicians' and district nurses' knowledge about medication routines was seen as a guarantee with regard to medicines in general and the medicine regimen in particular. The perceived strained work situation for HCAs risks placing older people in an adverse position in relation to HCAs with their heavy workload and limited schedules. This may negatively influence the care relationship and patient safety.

Relevance to clinical practice

Older people tend to have chronic diseases and be subject to multi-morbidity. This results in a broad spectrum of needs, including administration of medication, which must be met in the home over a long period of time. The responsibility of assistance with medication regimen is divided between two professional authorities, and the person him/herself. A well-functioning medication assistance based on a person-centred and holistic perspective is crucial to enable older people to remain at home with a perception of being safe and self-determining. A person-centred approach to health and social care delivery is efficient and leads to improved outcome for the recipient of care.

Contributions

Study design: ÅC, MW, EvS; data collection: ÅC, data analysis: ÅC, MW, LMH, and manuscript preparation: ÅC, MW, EvS, PH, LMH.

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Table 1.

Meaning unit	Condensed meaning unit Description close to the text	Condensed meaning unit Interpretation of the underlying meaning	Sub-theme	Theme
<p>I can not get medicine without a physician, not even get it (from the pharmacy) so I have to trust someone and I think it (the assistance) is okay... Well, I have so much (assistance) but I need it all.</p>	<p>The physician must prescribe medicine. It needs trust in someone who can provide the assistance I need.</p>	<p>Left out to trust health professionals and care providers</p>	<p><i>Health in transition leading to dependence</i></p>	<p><i>Balancing empowerment and dependence</i></p>
<p>P: I have not asked for it (assistance with administration of my medicine)but it suits me fine I: So it is unclear to you why you receive assistance. It just became this way? P: I am not sure. I think it could, it could, be that the physician has made the arrangement.</p>	<p>Could be the physician who arranged the assistance. Excluded from decision of assistance with medication but it turned out well.</p>	<p>Adjust to unrequested arrangement since it is for the best.</p>	<p><i>Balancing intrusion and respect for personal integrity and space</i></p>	
<p>P Well, it is a good thing (to get assistance). They are responsible for this (administration of medicine). As I said if they (home care assistants) have not administrated the afternoon medicine you can see it directly in the pill organizer. If so, I'll usually say that I'll take them now. But then they protest and say that if they are not taken in time, they should be thrown away. It happens now and then. I don't know who is right.</p>	<p>It is good to leave the responsibility of and get assistance with administration of medicines. Pill organizer is a safety control for missed dosage.</p>	<p>Pleased to leave the responsibility but reserve control for the safety.</p>	<p><i>Moving between trust, mistrust and control</i></p>	