

The considerations of informal caregivers in decision-making regarding a person with dementia who lives alone

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SUMMARY

Background: People with dementia have to make numerous decisions regarding daily life and wellbeing issues. Due to cognitive decline, a care network of formal and informal caregivers is involved in decision-making. It is expected that specific considerations play a role for informal caregivers in decision-making regarding a person with dementia who lives alone.

Objective: To gain insight in the considerations of informal caregivers when making decisions regarding a person with dementia who lives alone.

Method: A qualitative, multi-perspective, exploratory design. A secondary analysis was conducted on the interviews of five care networks around a person with dementia. This network consisted of a person with dementia, two informal caregivers and two formal caregivers. Each network member was interviewed three times during one year. 70 interviews were analyzed using principles of Grounded Theory.

Results Three underlying themes frame considerations of informal caregivers; 1) Provide wellbeing of the person with dementia 2) Comply to restrictions 3) Non-rational considerations. Each theme interacts with another, either conflicting or reinforcing.

Conclusion Making decisions for a person with dementia who lives alone is a difficult process. Providing wellbeing to the person with dementia whereby the person feels autonomous conflicts with having to comply to restrictions and decisions that are based on non-rational considerations. Findings highlight the importance of caregivers knowledge about dementia and insight in the decision-making process.

Recommendations Professionals who support informal caregivers in decision-making regarding a person with dementia who lives alone, should acknowledge that decision-making is a difficult process with counteracting considerations. Proxy decision-makers should be provided with knowledge about dementia and insight in the decision-making process. This could be provided by case managers or at informal meetings like 'Alzheimer café's'.

Key words: Dementia, Community dwelling, Family Caregivers, Decision Making

1. INTRODUCTION

During the illness trajectory of dementia, numerous decisions must be made regarding issues in daily life and wellbeing^{1,2}. These include areas of health care, finances, personal care, social activities, living arrangements and potential nursing home placement³⁻⁵. Since the ability to exercise choice contributes to autonomy and quality of life⁶, it is important that the person with dementia (PWD) is involved in the decision-making as long as possible⁷.

Shared Decision-Making (SDM) is a widely known approach which supports making decisions regarding care together⁸. Several different SDM models exist, most of them focusing on physician-patient dyad⁹. This is insufficient for persons with dementia. Due to progressive cognitive decline, people with dementia increasingly rely on caregivers to help them consider choices and make decisions. If they are no longer able to make autonomous decisions, most adults identify a family member to help them make decisions¹.

Research has shown that decision-making for a family member or friend with dementia can cause stress for the informal caregiver, such as determining their relative's decision-making capacity and weighing up what is in their best interest¹⁰. Professional support by nurses or case managers may help to decrease caregiver burden^{11,12}, including support in making decisions¹³.

Since a whole care network is involved in decision-making around a PWD, a SDM model in dementia should address this care network. The larger research project from which the present study is drawn addresses how SDM takes place in care networks of people with dementia. Within this research project, a SDM model described by Groen-van de Ven et al. (2014) shows SDM in dementia to be a dynamic, temporal and collaborative process. An important theme within this model is different perspectives of the network members. Close informal caregivers seem to focus on handling the present situation, whereas more distant informal caregivers tend to focus at preparing for the future by anticipating decisions that may become relevant¹⁴.

Other research showed that when it comes to deciding for and knowing the preferences and habits of the person they are supporting, spouse caregivers appear to have the strongest relationships, compared to adult children caregivers¹⁰. When people with dementia live alone, this usually means they don't have a spouse¹⁵. Based on the new insights of Groen-van de Ven et al. and Samsi & Manthorpe, it can be assumed that decision-making regarding a PWD who lives alone, in other words, who has an informal caregiver more at distance, is based on different considerations than that of people with dementia who have a spousal/in-living caregiver.

Government policy advocates that people should live on their own for as long as possible. Currently, about 44% of people with dementia live alone. The number of single persons over

70 is expected to increase by a quarter of a million in the next 20 years¹⁶. As a result, the number of people with dementia who live alone will increase¹⁷.

Research studies on proxy decision-making in dementia tend to focus on either patient-spouse dyad^{3,18,19} or on a mixture of informal caregivers (spouses, children, other family members or friends)^{4,10,20}. To our knowledge, no research has been conducted on how decisions are made specifically for persons with dementia who live alone. To be able to provide tailored nursing or case management support that fits the experience of informal caregivers, a better understanding of their considerations in the decision-making is needed.

2. OBJECTIVE

The aim of this study was to gain insight in the considerations of informal caregivers who are involved in decision-making regarding an person with dementia who lives alone.

3. METHOD

Design

This study used a qualitative, multi-perspective, exploratory design. This type of design is best suited because the topic of the study has not yet been examined extensively. It allows to describe in-depth views of participants on the subject researched²¹. The study is part of a larger ongoing research on shared decision-making in dementia. A secondary analysis was conducted using already existing data from a research that focused on how decisions are made in care networks of persons with dementia.

Participants and sampling

The population of the original study included care networks of people with dementia. Each network consisted of a PWD, two informal caregivers and two professional caregivers. Participants included in the original study met the following criteria: a diagnoses of dementia, the ability of the PWD to participate in an interview and the availability of at least one informal caregiver. The current study solely included networks of persons with dementia who live alone. In other words, community dwelling and without an in-living caregiver.

In the original study, the care networks were purposely selected, aiming for maximum variations regarding characteristics of the PWD (gender, socio-economic status and stage of dementia) and type of informal caregivers (spouses, children, other relatives or friends)¹⁴. Care networks were recruited via three routes; (1) healthcare organizations, (2) local meetings for informal caregivers and people with dementia, and (3) the website of the Dutch Alzheimer's Society¹⁴.

The original study included 23 networks of people with dementia. Five of these care networks involve a PWD who lives alone. Each care network consists of five members,

resulting in a total of 25 respondents for the current study. Each member of the care network is interviewed three times within a time lap of one year. Five formal caregivers withdrew in the third interview round, resulting in a total of 70 interviews available for this study (Figure 1).

Data collection

The original data were collected from July 2010 until August 2012. Three researchers and eight bachelor students (Nursing or Applied Gerontology) who were trained by the researchers, conducted semi-structured interviews. The interviews lasted one hour on average. The interviews were audio taped and transcribed verbatim. The interview guide comprised questions on how decisions are made in care networks of persons with dementia (appendix 1).

Analysis

Data from interviews were analyzed using principles of Grounded Theory. Grounded Theory is a systematic qualitative research methodology in the social sciences that allows researchers to study subjective experiences and to generate a model or theory by means of inductive categorization²³. First, a series of codes were extracted from the data²¹. These were grouped into categories by using affinity diagramming²⁴. This involved a session with two researchers and the coordinator investigator following predetermined steps of clustering codes, labeling clusters and defining categories. From these categories, themes were formed, which were the basis for the creation of a model. Interactions between the themes were established using a Conditional Relationship Guide²⁵. Nvivo software version 10 for Windows supported the analysis.

Several steps were taken to ensure internal validity and reliability. Two researchers (MH and LB) independently coded the first three interviews of informal caregivers. Differences in coding were face-to-face discussed until a common conclusion was drawn. Furthermore, the researcher made notes and memos during the process of analysis with the purpose of preserving theoretical and methodological decisions. Interim results were discussed with the coordinating investigator. By keeping an audit trail to ensure transparency, working systematically and using analyzing software, quality of the study was guaranteed²⁶.

Ethics

This study follows the ethical principles outlined in the revised Helsinki declaration²². Approval was given by the regional ethical board of the Isala Klinieken.

RESULTS

The demographic characters of the respondents are described in table 2. Three underlying themes framing considerations of informal caregivers arose in all interviews; 1) Provide wellbeing of the PWD 2) Comply to restrictions 3) Non-rational considerations. For each of the themes, the data show secondary categories that establish the specific considerations of the informal caregivers. Table 3 provides an overview of themes and categories.

<insert table 2>

<insert table 3>

Provide wellbeing of the PWD

This involves all considerations that are based on needs and wishes needs of the PWD. Either because the PWD expressed this explicitly, or because informal caregivers makes the decision himself with the best interest of the PWD at heart.

Respecting autonomy of the PWD This involves all decisions that are made on behalf of the PWD. Mostly because the informal caregiver knows that is what the PWD wants, either because PWD expressed this specifically, or because they are familiar with his/her wishes and habits. Informal caregivers find it important to respect the character of the PWD. Decisions are made, for example, because 'he always used to do it like this' or not sending the PWD to daycare because 'he was never one to be in a group'.

Respecting autonomy also means not wanting to force and/or patronize the PWD, and taking decisions slowly and step by step.

"And then I said to home care; you know what, leave it, we shouldn't. You tried. But if he doesn't want to, he doesn't want to, you can't force him".

- Daughter, care network (CN) 2

Preserve calmness This involves all decisions that intend to provide the PWD with continuity and structure, and prevent the PWD to become disquiet and agitated. Continuity and structure are mostly provided by making sure there is a limited amount of caregivers. A daily structure is achieved through structural care, daycare and tools like a big clock or calendar. Interventions to prevent agitation varies from leaving the PWD at home to prevent distress, to not involving the PWD in conversations about his situation.

" And [name care organization] placed her [PWD] in a different postcode district, so she suddenly got other caregivers, but we were able to turn that back."

- Son-in-law, CN 3

Promote mental wellbeing PWD This involves all considerations that intend to provide good care to the PWD, and make him feel content. This entails interventions, which the PWD shows, verbally or non-verbally, to like and feel good about. This could mean providing care, sometimes counterintuitive to the caregiver. For example keeping a maid who does her job insufficiently according to informal caregiver. However, the PWD enjoys it when she comes over.

“For example canceling the newspaper, he does not read it anymore, but we don’t cancel it. He [PWD] has always been very much aware of the latest news. It’s a pity that he doesn’t read the newspaper anymore, but we leave it here. Because he still has the idea that he can read”

- Daughter, CN 2

Promote physical and social wellbeing of PWD This mainly involves wanting to break solitude of the PWD. The decision might be to start daycare, or to make sure to visit regularly, although never against the explicit wishes of the PWD.

Another part of this category is to promote health of PWD, for example by making sure he eats varied and regularly, and takes his medication on time.

‘She got more help because she felt lonely. So now someone also visits her in the afternoon. Another reason was because we noticed that she was eating poorly [...] and if someone comes over, we’re sure she eats’.

- Daughter-in-law, CN 4

Comply to restrictions

There are limits in to what extent wishes of the PWD can be met. The data suggest that informal caregivers encounter limitations in several areas. These concern caregiver burden, safety issues and feasibility.

Decrease caregiver burden This involves making decisions that intend to decrease caregiver burden. This can mean lowering their commitment, like reducing the number of visits to the PWD. This may also mean interventions which aim to ensure that caregiver burden is relieved, such as homecare. Also, this includes decisions that anticipate further cognitive decline of the PWD (e.g. nursing home enrollment). Finally, because the caregivers worry about the wellbeing of the PWD who is home alone a lot, this includes decisions that lead to the informal caregiver being reassured about the wellbeing of the PWD.

“Yes, homecare three times a day. And of course, that reassures us that three times a day someone comes along. So if she would fall or something would happen she is not hours or maybe a day or two home alone.”

- Nephew, CN 5

Securing safety of the PWD. This can range from relatively minor house-adjustments (e.g., removing rugs to prevent falls), to the deployment of more care, letting the PWD give up driving or even enrolling the PWD in a nursing home. When the safety limit is exceeded action is being taken. In general, this goes against the will of the PWD and is in some cases counterintuitive of the informal caregiver.

“As long as she is doing good, she stays here at home, absolutely. [...]Really, I would hate it if I have to place her in a nursing home, but if she do not know, if she's really that sick, then we'll have to someday”.

- Daughter-in-law, CN 4

Feasibility. Some decisions are limited by practical reasons. Informal caregivers reach the limits of the possibilities. It may involve costs, practical issues and to 'not have a choice' for several reasons. The idea not to have a choice is either the result of the physical wellbeing of the PWD, or having reached the maximum capacity of home care which leads to the decision to enroll the PWD in a nursing home. Choosing a nursing home can be based on distance to the residence of the informal caregiver which makes it easier to come visit.

“She could stay there [rehabilitation nursing home] for six or eight weeks and then we needed to place her somewhere, because going back home wasn't an option. We have considered 24-hour home care, but that's just very expensive”.

- Daughter-in-law, CN 4

Non-rational considerations

Data shows that next to provide wellbeing for the PWD and complying to restrictions, informal caregivers have other resources they base their decisions on. In these cases, there is not necessarily an explicit consideration involved. Decision-making can be best described as be taken somewhat intuitive.

Rely on intuition and experience. Some informal caregivers have experience with dementia from another relative. Data suggests that caregivers with experience dare to let things be and rely on a good outcome. They know there is no use in forcing things, and some things have a way of 'resolving itself'.

"We have already received a lot of information when my mother-in-law was suffering from dementia [...]. We learned that you have to grow into things. You cannot force things"

- Daughter, CN 1

Surrender to emotions. In some cases, caregivers find it hard to make decisions, especially when this involves going against the will of the PWD. Mostly, this involves nursing home enrollment. As a result, such decisions are postponed. In these cases, informal caregivers do not so much rely on their intuition as they seem to surrender to emotions.

"And I find it difficult to ... enroll her somewhere [in a nursing home], I must though.. because something may happen at once, and then she would be enrolled nowhere. Well, her wish is to stay as long as possible here. I think I should respect that.

Yes .. .and now I think there is sufficient help.. .for now she is adequately monitored. So I wanted to leave temporarily run its course.

And then ..eh we will see. "

- Daughter, CN 1(1)

"His daughter finds it very difficult to say that he should accept help with ADL. She has appointed this in his presence because I wanted to. But then he got very angry and then she stopped trying pretty quickly.

Then she says: leave it, we will see where it escalates"

- Casemanager, CN 2

Rely on professionals. In most cases multiple formal caregivers are involved. Some decisions are made by the informal caregiver by relying on these professionals. Many informal caregivers are new to dementia and everything it entails, and struggle to make decisions. Therefore they find it comforting that someone is there to give guidance and to help consider choices.

"Yes, she [wait list mediator nursing home] asks how it goes. Based on my story she said the last time 'we will place her on an active list'. I said 'that sounds like a good idea'.

But actually, I have no idea what it means."

- Nephew, CN 5

“Yes, well, I would say that if the [home care organization] notices she needs more personal care, they would let me know. You see, I wouldn’t notice it myself.”

- Niece, CN 5

Interaction of the themes

The three themes are linked to each other. Whereas theme 1 and 3 conflict with and reinforce each other, theme 1 and 2 solely conflict. Figure 2 contains the interaction of the themes in a model.

<insert figure 2>

4. DISCUSSION

This study was a first exploration to gain insight in which considerations play a role for informal caregivers who are involved in decision-making for a PWD who lives alone. Data show three underlying themes; 1) Provide wellbeing of the PWD 2) Comply to restrictions 3) Non-rational considerations.

Several studies already established that making decisions for a PWD is a difficult process, because the interests of all parties involved in decision-making need to be taken into account^{10,13,27}. This study confirms this conclusion for a PWD who lives alone. The different considerations of caregivers interact with each other. Wanting to respect autonomy of the PWD is often in conflict with restrictions as caregiver burden, safety issues and feasibility. Also, this study confirms earlier findings that making decisions for a relative is only to a certain extent a rational matter²⁸, because emotions and intuition of the informal caregiver play a role in decision-making. Moreover, informal caregivers with experience in taking care of a PWD seem to have a different attitude toward making decisions, because of their knowledge of dementia. These caregivers more often rely on a good outcome and dare to let things be to resolve itself. Their reliance on intuition and experience is likely to influence psychological caregiver burden in a positive way.

Wanting the PWD to feel good and autonomous is important for caregivers when making decisions regarding a PWD who lives alone. Based on other research, it is expected that this plays a less important role in time. Findings of Reamy et al.²⁹ show that caregivers increasingly de-emphasize the importance of values of the PWD²⁹. This can be explained by the fact that cognitive decline results in a greater role for safety issues and caregiver burden.

Unsurprisingly, caregiver burden plays a role for the non in-living informal caregivers in decision-making, although this is partly different than for spousal caregivers^{3,18,19}. Other than spouses, caregivers caring for a PWD who lives alone deal with the ‘psychological

burden' of worrying about the wellbeing of the PWD who is home alone most of the time. Actions are taken (e.g. home care, day care) aiming to decrease worry of the caregiver.

This study nuances the findings of L. Groen-van de Ven, who found that close informal caregivers focus on handling the present situation, whereas more distant informal caregivers tend to focus on preparing for the future¹⁴. This might be the case if the caregiver at distance is not the first proxy decision maker, in other words, when a spousal (in-living) caregiver is also present. However, decisions anticipating the future are more difficult for the informal caregiver at distance (not-in-living) if he is the first proxy decision-making, so when there is no spousal caregiver present. This might have to do with having decision-making responsibility. Decisions anticipating the future are often against the will of the PWD, for example when it comes to nursing home placement. Because of the emotions that play a role for caregivers when having to overrule autonomy of the PWD, such decisions are postponed.

Although the importance of professional care in making proxy decisions is already widely accepted^{30,31}, the results of this study further emphasize the role of health care professionals. By understanding the process informal caregivers go through in decision-making for a PWD who lives alone, strategies can be considered that provide informal caregivers with knowledge and support.

Conducting a secondary analysis has its limitations. The conclusions that were drawn from the contents of the transcribed interviews are limited, because the interviews focused on how decision-making takes place in care networks around a PWD, not specifically to elicit information about specific considerations of informal caregivers in decision-making. Secondly, since the data were not collected by the researcher, it was more difficult to become fully familiar with the data. An effective communication link with the principal researcher who was involved by generating the data, made sure additional questions about the data could be clarified. Moreover, steps of Grounded Theory could not be strictly followed because of a lack of control in generating the data,. To follow Grounded Theory methods, theoretic sampling must be used. It requires ongoing generation of new data based on the emerging categories from the analysis until no new themes emerge²³. However, as a result of a rich database, theoretic saturation was nevertheless reached. The advantage of making use of already existing data is its efficiency and allowing to be sensitive regarding respondent burden.

The findings of this study are the result of an preliminary exploration. More extensive research specifically formulated to explore informal caregivers' considerations in decision-making regarding a PWD who lives alone could provide more in-depth information. Future research is also required to establish whether these considerations change over time. Moreover, professional guiding strategies need to be developed that address the need of informal caregivers in support in the complex process of decision-making.

CONCLUSION

This exploratory study examined which considerations play a role for informal caregivers when making decisions regarding a PWD who lives alone. The findings revealed three interacting themes. Providing wellbeing to the PWD whereby the PWD feels autonomous, conflicts with having to comply to restrictions and decisions that are based on non-rational considerations. Being the first proxy decision-maker makes it harder to make decisions anticipating the future, whereas being experienced in taking care of a PWD seems to decrease caregivers decision-making burden. These findings highlight the importance of caregivers knowledge about dementia and insight in the decision-making process.

RECOMMENDATIONS

Professional caregivers should acknowledge that being the first informal decision-maker for a PWD who lives alone is difficult, because of the conflicting considerations of the informal caregiver. Informal caregivers who are involved in decision-making regarding a PWD who lives alone would benefit from information and educational materials designed to improve knowledge of dementia as well as insight in the complex process of decision-making. Information could be provided by nurses or case managers, or at informal meetings about dementia such as 'Alzheimer Café's'.

CONFLICT OF INTERESTS

None

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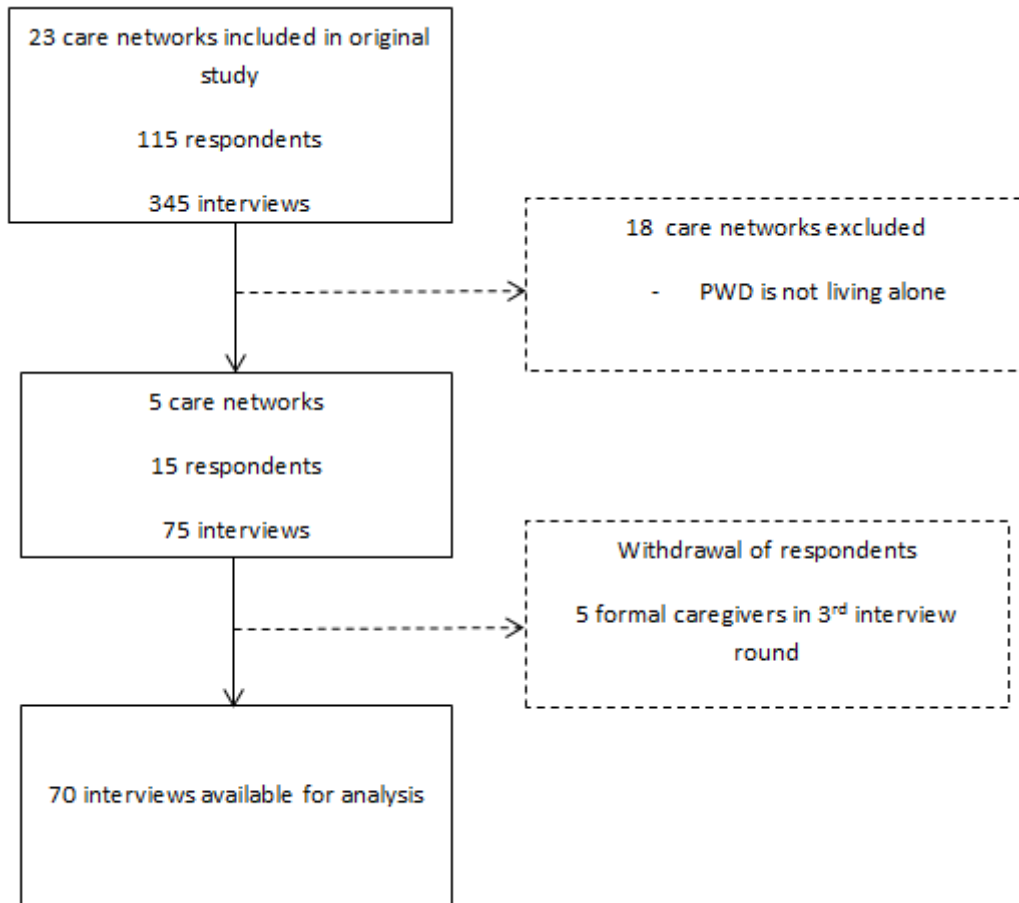


Figure 1 Flowchart Inclusion of interviews

Appendix 1: TOPIC GUIDE ORIGINAL STUDY

Table 1 Topic guide original study

Subject	Topics and questions for person with dementia	Topics and questions for the informal caregivers	Topics and questions for the professional caregivers
General information	Age Former profession Ethnicity Gender Living accommodation (Community dwelling/home for the elderly/nursing home)	Gender Relationship with the person with dementia	Professional background Tasks related to care of person with dementia Type of organisation where professional works Team composition Involved in care for person with dementia since when? Diagnosis of person with dementia (by whom and what is it?) Professional assessment of the stage of dementia
Decisions	<ul style="list-style-type: none"> • How are you? • What has changed for you lately? • What choices have you had to make because of these changes? • What do you think about your decisions now? 	<ul style="list-style-type: none"> • How do you feel [name of the person with dementia] is doing at the moment? • What has changed for the person with dementia lately? • What choices have you had to make because of these changes? • What do you think about your decisions now? 	<ul style="list-style-type: none"> • What has changed for the person with dementia lately? • What choices have you had to make because of these changes? • What do you think about your decisions now?
Decision-making	<ul style="list-style-type: none"> • What was the cause of the decision? • What happened before the decision was made? • Who was involved? • What was your role in making this decision? • What did you want? What made this important to you? • What did others want? What made this important to them? • What were the alternatives? • How did you manage to reach a decision together? • What information did you need to reach a decision? 	<ul style="list-style-type: none"> • What was the cause of the decision? • What happened before the decision was made? • Who was involved? • What was your role in making this decision? • What did you want? What made this important to you? • What did others want? What made this important to them? • What were the alternatives? • How did you manage to reach a decision together? • What information did you need to reach a decision? 	<ul style="list-style-type: none"> • What was the cause of the decision? • What happened before the decision was made? • Who was involved? • What was your role in making this decision? • What did you want? What made this important to you? • What did others want? What made this important to them? • What were the alternatives? • How did you manage to reach a decision together? • What information did you need to reach a decision?

Table 2 Participants characteristics

Care Network	Gender of PWD	Age of PWD	Stage of dementia¹	Marital status	Type of informal caregivers interviewed	Type of formal caregivers interviewed
1	Female	83	B	Widowed	Daughter Friend	Employee of day-care-centre Case manager at mental health organization
2	Male	80	B	Widowed	Daughter Son	Home care nurse Case manager at home care organization
3	Female	89	M	Widowed	Daughter Son-in-law	Principal home care nurse Case manager
4	Female	87	M	Widowed	Daughter-in-law Daughter-in-law	Principal home care attendant Case manager
5	Female	89	B	Single	Nephew Niece	Principal home care nurse Care coordinator
¹ Judged by professional interviewer B = Beginning dementia, M = Moderate dementia, PWD = person with dementia						

Table 3 Overview themes and categories

Theme 1 Provide wellbeing of the PWD	Respect autonomy
	Promote mental wellbeing
	Preserve calmness
	Promote physical and social wellbeing
Theme 2 Comply to restrictions	Decrease caregiver burden
	Safety issues
	Feasibility
Theme 3 Non-rational considerations	Rely on intuition and experience
	Rely on professionals
	Surrender to emotions

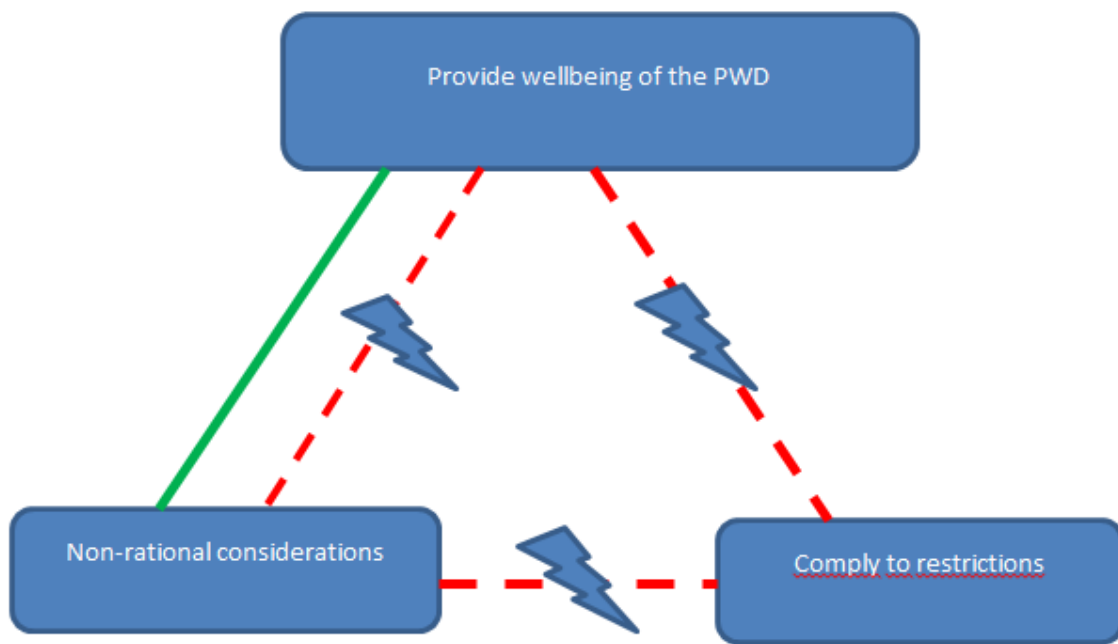


Figure 2 The model of considerations of informal caregivers when making decisions regarding a PWD who lives alone

