

**Making decisions about the care- and treatment plan during
multidisciplinary consultation in dementia care**

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ABSTRACT

Background: In nursing homes, decisions concerning daily living, values and preferences regarding the lives of residents with dementia, are established in a person-centred care- and treatment plan. This plan is being determined during the multidisciplinary consultation which is attended by professionals and sometimes caregivers. Residents should be involved in decision-making to determine a person-centred care- and treatment plan because making decisions and sharing preferences has a positive influence on quality of life.

Research questions: ‘What are the experiences of caregivers of residents with dementia regarding the determination of the care- and treatment plan during the multidisciplinary consultation?’ and ‘To what extent does the care- and treatment plan as determined in the multidisciplinary consultation align to the values and preferences according to residents with dementia and their caregivers?’.

Method: A multi-perspective qualitative study using semi-structured interviews with five residents and seven caregivers in a Dutch nursing home. The first two steps of QUAGOL were used to prepare the data, followed by open and axial coding.

Results: 57 Codes, nine categories and two themes, representing the research questions, emerged. Overall, caregivers were satisfied about the content of the multidisciplinary consultation; the care- and treatment plan was shortly being discussed and determined. A lot of medical related topics were discussed instead of different values and preferences which were considered important by residents and caregivers.

Conclusion: The study findings indicate that an optimal discussion about values and preferences during the multidisciplinary consultation did not emerge. It was unclear based on the interviews if important values and preferences were recorded in the care- and treatment plan.

Recommendations: Future research should focus on involvement of residents in making- decisions outside of and during the multidisciplinary consultation, because residents are able to indicated their values, preferences and wishes.

Keywords: Dementia, multidisciplinary consultation, care- and treatment plan, decision-making.

NEDERLANDSE SAMENVATTING

Achtergrond: In het verpleeghuis worden beslissingen omtrent het dagelijks leven, waarden en voorkeuren van het leven van bewoners met dementie vastgelegd in een persoonsgericht zorgleefplan. Dit plan wordt vastgesteld in het MDO in aanwezigheid van professionals en soms naasten. Om een persoonsgericht zorgleefplan vast te stellen moeten bewoners betrokken worden bij het maken van beslissingen omdat het maken van beslissingen en delen van voorkeuren een positieve invloed heeft op de kwaliteit van leven.

Onderzoeksvragen: ‘Wat zijn de ervaringen van naasten van bewoners met dementie met het vaststellen van het zorgleefplan tijdens het MDO?’ en ‘In hoeverre sluit het zorgleefplan wat vastgesteld wordt in het MDO aan bij de waarden en voorkeuren volgens bewoners met dementie en hun naasten?’

Methode: Een multi-perspectieve kwalitatieve studie met semigestructureerde interviews met vijf bewoners en zeven naasten in een Nederlands verpleeghuis. De eerste twee stappen van de QUAGOL zijn gebruikt om de data voor te breiden, gevolgd door open en axiaal coderen.

Resultaten: 57 Codes, negen categorieën en twee thema's gelijk aan de onderzoeksvragen zijn ontstaan. Over het algemeen waren naasten tevreden over de inhoud van het MDO; het zorgleefplan werd kort besproken en vastgesteld. Er werden veel medisch gerelateerde onderwerpen besproken in plaats van verschillende waarden en voorkeuren welke als belangrijk werden aangeduid door bewoners en naasten.

Conclusie: De gevonden studieresultaten geven aan dat een optimale discussie over waarden en voorkeuren tijdens het MDO niet ontstond. Op basis van de interviews werd het niet duidelijk of belangrijke waarden en voorkeuren werden vastgelegd in het zorgleefplan.

Aanbevelingen: Toekomstig onderzoek zal zich moeten focussen op het betrekken van bewoners tijdens het maken van beslissingen buiten en tijdens het MDO omdat bewoners in staat zijn hun waarden, voorkeuren en wensen aan te geven.

Trefwoorden: Dementie, multidisciplinair overleg, zorgleefplan, besluitvoering.

INTRODUCTION

In the Netherlands, 70.000 people with dementia are living in nursing homes¹⁻³. The goal of nursing homes is to deliver care which contributes to quality of life of residents with dementia. In order to achieve this, residents should be involved in making decisions concerning their daily living and treatments^{4,5}. Residents have the right to make decisions and receive care based on their values and preferences recorded in a person-centred care- and treatment plan^{6,7}. Making decisions and sharing preferences has a positive influence on quality of life⁸⁻¹⁰.

However, it appears that residents are prematurely excluded in decision-making¹¹. Dementia reduces mental competences^{12,13} and influences the ability to weigh-out options and make decisions. Therefore, residents may rely on their informal caregivers for decision-making^{10,14}. Informal caregivers are also essential to the residents quality of life¹⁵.

The care- and treatment plan (CTP) in a nursing home is being discussed during the multidisciplinary consultation (MDC). The MDC has the purpose to evaluate and adjust the CTP, exchange information, and determine the medical policy, at least twice a year¹⁶. Aim is to establish a CTP which is adapted to the daily living, preferences and values of the residents¹⁷, thereby increasing welfare and quality of life¹⁶. An CTP is important because the care provided by nursing home professionals is based on this plan⁹. In a Dutch nursing home, MDC's are attended by professionals and sometimes caregivers. The CTP is being discussed and caregivers can give input. Despite the fact caregivers attend an appointment with the first responsible nurse to talk about the CTP before the MDC, they are not always present at the MDC. Reasons for low attendance are unknown, but might be influenced by professionals excessive use of jargon¹⁸. In addition, residents are not attending any of the consultations.

In the desired practice, MDC's are attended by professionals, caregivers and residents to determine a person-centred CTP based on values and preferences. Aim of this study is to explore experiences with the determination of the CTP in the MDC, and to explore values and preferences according to residents and their caregivers.

RESEARCH QUESTIONS

1. 'What are the experiences of caregivers of residents with dementia regarding the determination of the care- and treatment plan during the multidisciplinary consultation?';
2. 'To what extent does the care- and treatment plan as determined in the multidisciplinary consultation align to the values and preferences according to residents with dementia and their caregivers?'

METHOD

Design

A generic qualitative study design^{19,20}, using semi-structured interviews²¹, was used to explore experiences of caregivers with the current MDC. Also values and preferences from perspectives of residents with dementia and their caregivers, represented in the CTP determined during the MDC, were explored^{19,20}. A generic qualitative design suited the study due to the exploration of experiences and little knowledge about this specific topic²².

Population

The study population consisted of 62 residents with dementia living at six psychogeriatric Dutch nursing home wards, and their caregivers. A purposive sample based on gender, age and type of dementia was used to capture a wide range of perspectives of residents and their caregivers^{23,24}. Inclusion criteria for residents were: diagnosis dementia, able to attend an interview, and understand and speak Dutch. Terminal residents were excluded. To participate, caregivers had to be a relative of the resident and had to participate in the MDC twice a year. Caregivers of terminal residents were excluded.

Procedures/data collection

Based on inclusion criteria, a total of 22 residents and their caregivers were indicated as eligible participants by the physician, psychologist and first responsible nurse. Sixteen residents were not able to attend an interview, ten residents did not understand/speak Dutch and fourteen caregivers did not (yet) participated in the MDC because their parent was recently admitted. Caregivers of eligible residents received an information letter about the study.

Initially, two caregivers responded and agreed to participate. Five other caregivers were recruited after the researcher phoned them.

Interviews were planned after consulting caregivers and residents. Two separate interview guides were developed: one for caregivers to answer both research questions, one for residents to answer the second research question (table 1). Interview guides were based on existing studies^{14,25-28}. One pilot-interview was taken to test the interview guide. Preferably, both the resident and his/her caregiver were interviewed. Interviews with caregivers were face-to-face, interviews with residents were attended by the caregiver or a nurse.

All interviews took place in the residents' room or a family-conversation room. The interviews lasted on average 24 minutes, and were audio-recorded using a voice recorder. Interviews were conducted by one researcher from February 2018 until May 2018. The researcher had little experience with interviewing and worked for five years as a nurse with people with dementia. Participants were included until data saturation emerged^{29,30}.

Data analysis

All interviews were transcribed verbatim and data was prepared using the first two stages of the QUAGOL method³¹. In stage one, transcripts were thoroughly read multiple times. Narrative interview reports were made in stage two, representing an abstract with key storylines including an impression of the interview characteristics. The reports were sent to the caregiver as a member check, a few caregivers provided feedback.

When the researcher was familiar with the data, the first five interviews were open coded, resulting in fragments which were giving a code. A second researcher gave feedback on these codes and the other seven interviews were coded. During a meeting, with two researchers and a peer-student, all codes were discussed and compared. Corresponding codes were clustered and assembled to one category using affinity diagramming³². While discussing, codes were pushed back and forth by the researchers and student. Finally, the codes and categories were determined in joint consultation. During a second meeting, codes and categories were discussed again with a second researcher. Memos made during the interviews were used during analysis. NVivo software (ORS International, Australia)³³ was used for the analysis³⁴.

Ethical issues

The regional ethical committee of the Isala Klinieken, Zwolle, the Netherlands, approved this study (number 180203). Double informed consent was requested; both the resident and their caregiver signed for participation.

RESULTS

Of the 22 eligible residents, a total of seven residents agreed to participate. In four cases both the resident and their caregiver participated, in one case two caregivers participated, in one case the caregiver participated and in one case only the resident participated. Twelve interviews were conducted. Residents who participated consisted of four women and one man in the age range from 83 to 92. Four residents had Alzheimer's, two had vascular dementia and one had Parkinson's dementia. Caregivers who participated were all daughters in the age range from 48 to 68. Demographic data is stated in table 2.

After analysis, 57 codes divided in nine categories emerged. The research questions are represented by two themes: (1) experiences of caregivers of residents with dementia with the MDC and, (2) values and preferences according to residents with dementia and their caregivers in relation to the CTP. Codes are illustrated using quotes (Q..) in table 3.

Theme 1: experiences of caregivers of residents with dementia with the MDC

Information in this theme is based on interviews with caregivers. Experiences of caregivers with the MDC and the determination of the CTP are represented. This theme consists of five categories: (1) moment to exchange knowledge, (2) focus on medical topics, (3) making decisions, (4) limited time for optimal discussion, and (5) role of first contact person. Caregivers were satisfied about the overall manner of working during the MDC where the CTP was shortly being discussed, modified and determined. A notable finding was the focus on medical related topics.

Moment to exchange knowledge

Caregivers experienced the MDC as a moment to exchange knowledge with the nursing home professionals. Caregivers exchanged information they considered important, for example who their parent was/is and how their parent wants to be treated. Caregivers mentioned they were being involved by professionals and talked about ways for the best care, hereby sharing their visions and experiences about the daily living of their parent. Room to share and discuss things during the MDC was experienced as important and pleasant (Q1, Q2). Caregivers became aware of the facts when professionals discussed the state of affairs (Q3). Despite the general pleasant experiences of caregivers, one caregiver said professionals used unclear jargon (Q4); things that were said were not clear.

Focus on medical topics

Various topics concerning the care were being discussed during the MDC. Topics were different within each resident, but what stood out were the amount of medical topics; medical treatment/medication (Q5), regression because of dementia, and physical functioning (Q6). The topic activities/things to do was scarcely addressed during the MDC. However, caregivers tried to talk about daily activities because they found that was important to their parent (Q7). Caregivers indicated the connection between dementia, mood/depression (Q8) and loss of loved ones (Q9), but these topics were discussed superficially.

Making decisions

During the MDC, the CTP was being discussed and decisions regarding to the plan were made. Caregivers experienced involvement in weighing decisions (Q10), they could tell their vision and ideas before decisions were made. Making decisions happened in dialogue with different professionals (Q11) and sometimes the resident was being involved. Caregivers took expressed wishes from residents into account while making decisions. Unfortunately, not all decisions were made in dialogue with caregivers. For example, medication change was not discussed (Q12).

Limited time for optimal discussion

Overall, caregivers mentioned an optimal discussion of the CTP could not take place because of the short duration of the MDC. Several professionals were present at the MDC; psychologist, physician, and first responsible nurse. Jointly with caregivers, the CTP was being discussed (Q13), which was being experienced as pleasant. Unfortunately, time was going fast (Q14). A few caregivers mentioned the lack of depth during the MDC, especially about the topics consequences of dementia and the psychological side (Q15). One caregiver found a lack of structure (Q16) thereby giving her the impression she was missing out on information. Because of the limited time, some topics were being discussed in the corridors of the ward instead of during the MDC (Q17). Caregivers indicated discussing CTP topics in the corridors of the ward as good intermediate solution, they reconciled oneself with this way of working.

Role first contact person

Caregivers explained they participated in the MDC as a representative for their parent. Nearly all caregivers mentioned that they know their parent better than anyone else does (Q18). They stay involved by reading the CTP and the dossier (Q19, Q20). Caregivers mentioned indicating boundaries/limits, often based on expressed wishes of their parent a few years before the dementia, as important to propagate (Q21). They indicated this as their job to defend the wishes of their parent because most residents were no longer able to do so themselves.

Theme 2: values and preferences according to residents with dementia and their caregivers in relation to the CTP

Information in this theme is based on interviews with residents and caregivers. Values and preferences, and to what extent these values and preferences correspond to the CTP are represented. The theme consists of four categories: (1) values of residents/caregivers regarding the care- and treatment plan, (2) preferences to get through the day, (3) habits based on life story, and (4) perceived value of the care- and treatment plan.

Different values, preferences and habits were important to residents and their caregivers. Unfortunately, these were (almost) not being discussed during the MDC. Also, important values and preferences were missing in the CTP.

Values of residents/caregivers regarding the care- and treatment plan

Various important values can contribute to the welfare of the residents when being addressed in the CTP. Half of the mentioned values was being described in the CTP. For example, maintaining your own direction and freedom. It was considered important to do the things you always did and to make your own choices (Q22, Q23). During interviews, residents talked about things they thought were cosy (Q24). Cosiness was in line with the CTP (Q25). A safe residential/living environment was mentioned several times and described in the CTP. About respect and a respectful approach, a caregiver mentioned her mother appreciates the way nurses speak to her (Q26). Other values, like privacy (27) were mentioned several times, but a relation with the CTP was not found during interviews. One resident mentioned her independency was not respected by nurses (Q28), because nurses took things out of her hands, an unpleasant experience. Sometimes there was a misunderstanding about an appointment stated in the CTP (Q29).

Preferences to get through the day

Preferences differed per individual, although, a lot of similar preferences were indicated. Most of the important preferences were being described in the CTP and contributed to the residents' quality of life according to caregivers. Going outside was mentioned frequently. Some residents were allowed to leave the ward and go outside for a walk, they were fond of this. Appointments about going outside were made and recorded in the CTP (Q30). Listening to/experiencing music was also an important preference (Q31). A daughter mentioned her mother is being involved within music activities and her mother is pleased with this. The preference playing games was discussed during the CTP meeting with the first responsible nurse (Q32), upon which the CTP was adjusted.

Habits based on life story

Residents and caregivers mentioned a lot of habits based on residents' life story. These habits were not described in the CTP, or it was unknown if habits were described. Habits provided information about things residents liked/loved to do, or things important to them. These habits can contribute to the welfare of the residents when being introduced in the CTP. Social contact(s) was a main topic for all residents and caregivers (Q33). Coherent with social contacts was children/family (Q34). Residents were happy having their children around. Doing things for someone else and being of value/important to someone (Q35) was important according to residents. Needlework/create activities are habits residents loved to do, however, they sometimes depended on others for this activities (Q36). Eating was mentioned several times (Q37), partly in conjunction with cosiness.

Perceived value of the care- and treatment plan

To deliver quality of care, a CTP has to be adapted to the values and preferences of residents. But, almost all caregivers mentioned the CTP was not up-to-date (Q38), things were not applicable or essential things were missing (Q39). Important values and preferences were also missing (Q40). One caregiver mentioned here values and preferences were more represented in the CTP than her father's (Q41). The added value of the CTP was questioned by caregivers. The way nurses acted was considered more important than a CTP (Q42). Especially when the CTP did not match with the values and preferences of residents and their caregivers.

DISCUSSION

Main findings

During the MDC, caregivers and nursing home professionals briefly discussed, modified and determined the CTP. The way of working during the MDC was overall experienced as pleasant. Caregivers went to the MDC to obtain and provide information, and to discuss visions, experiences, and topics with professionals. But, optimal discussion was not achievable, possibly caused by a lack of time. However, caregivers found a way to discuss important things regarding the CTP outside of the MDC and did not see the limited time as a limitation.

Outstanding finding was the discussion about mainly medical related topics during the MDC.

This is contrasting with things that were considered important by residents and caregivers. Daily living of residents and values and preferences as topics were (mostly) not discussed in MDC's. In most cases experienced care was in line with values and preferences of residents and caregivers, but it was unclear if these values and preferences were actually recorded in the CTP. Although, caregivers valued the way care was provided more than a CTP.

Findings compared to literature

This study showed an optimal discussion was not always achievable during the MDC. Literature shows MDC's in healthcare stimulates discussion between patients, relatives and professionals when patients/relatives are well-prepared²⁷ and informed about the purpose and expectations³⁵. Social health themes were almost not being discussed during the MDC in comparison to medical themes. According to literature, person-centred care based on social health, for example goals aligning with residents' preferences, resulted in a significant improvement of the amount and intensity of physical activity within residents with dementia in nursing homes³⁶⁻³⁸.

Interviews showed almost all decisions were taken by caregivers, sometimes in consultation with residents or based on residents wishes. Also, residents were able to tell what they consider important; they indicated values, preferences and wishes regarding their own life. Literature shows residents may rely on their caregivers for decision-making^{10,14}, but, residents also want to participate in decisions regarding their life^{26,39,40}.

Strengths & limitations

This study had several strengths and limitations. One strength was the participation of residents with dementia. Information about values and preferences according to residents was collected, showing residents are able to attend interviews and tell about things they consider important.

A second strength was the use of narrative interview reports. All participants received a report as member-validation to check the internal validity^{19,21}, and all participants agreed with the report. The third strength is the fact that a purposive sample emerged which contributes to the validity of the results.

A limitation of this study was due to the fact caregivers and one nurse attended the interviews with residents, which may have influenced the residents' responses. An attempt was made to limit this chance by asking caregivers and the nurse not to answer questions asked by the researcher. Finally, the intention was to use an iterative process in which data collection and analyses alternate each other to adjust the interview guide for more depth during interviews. Unfortunately, due to limited time between the interviews this process was not used.

Implication for clinical practice

Experiences of caregivers can be used to shape the content of the MDC in a different way. Nursing home professionals should tell caregivers the purpose and expectations of the MDC to stimulate an optimal discussion. A lot of medical related topics were discussed during the MDC, while the focus also has to be on daily living and important values and preferences. The values and preferences can form together with social health a basis for a person-centred CTP for residents when being discussed in the MDC.

Future research

This study showed residents are able to indicate values, preferences and wishes regarding their own life. So, future research should focus on involving residents with dementia in decision-making about their daily living at the nursing home. Also making decisions, based on values and preferences, with the focus on social health, in consultation with caregivers and nursing home professionals could be explored.

Conclusion

The aim of the study was to get insight in experiences of caregivers with the determination of the CTP, based on the values and preferences according to residents with dementia and caregivers, during the MDC. The findings indicate an overall satisfaction about the current MDC. Despite this, a discussion about important values and preferences during the MDC is not yet optimal. And, notwithstanding, experienced care was in line with values and preferences, improvements to the recording of these values and preferences in the CTP can be made.

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TABLES

Table 1 Interview guides

Interview guide voor naasten	
Topics	Vragen
Openingsvraag	- Wat is op dit moment het belangrijkste voor uw naaste volgens u? <i>Mogelijke aanvullende vraag: in hoeverre wordt u betrokken in de zorg rondom uw naaste? Vragen om toelichting mogelijk.</i>
Zorgleef- en behandelplan	- Wat is in het algemeen belangrijk voor uw naaste? <i>En waarom is dit zo belangrijk? Kunt u hier meer over vertellen? En hoe geldt dit voor u? Mogelijke geschiedenis van iemand meenemen.</i> - Welke wensen zijn in het algemeen belangrijk voor uw naaste? <i>En waarom is dit zo belangrijk? Kunt u hier meer over vertellen? Wat zijn gewoonte van uw naaste? Wat doet uw naaste graag? En hoe geldt dit voor u?</i>
Multidisciplinair overleg	Hoe ziet u belangrijke wensen en waarden terug in het MDO? <i>Doorvragen op eerder benoemde wensen en waarden.</i> Wat is uw ervaring met het MDO? <i>Kunt u hier iets over vertellen?</i> Hoe ziet u uw rol binnen het MDO? <i>En waarom ziet u die rol zo?</i> In hoeverre wordt u door professionals betrokken tijdens het MDO? <i>Wordt u in de gelegenheid om vragen te stellen of worden er vragen aan u gesteld?</i> Wat vindt u van de onderwerpen die besproken worden in het MDO? <i>In hoeverre zijn deze onderwerpen van belang volgens u? En waarom? Komt datgeen dat besproken wordt overeen met wat uw belangrijk vindt dat besproken wordt? Hoe wordt u betrokken in de onderwerpen die besproken worden in het MDO?</i>
Gezamenlijke besluitvorming	Hoe ervaart u beslissingen t.a.v. het zorgleefplan die genomen worden in het MDO? <i>Hoe ziet u dit terug in de zorg en begeleiding van uw naaste? Doorvragen, hoe wordt u hierbij betrokken? Wat gaat goed en wat kan beter?</i> Welke afspraken over uw naaste zullen er gemaakt moeten worden volgens u? <i>Waarom? Welke van deze afspraken worden nu besproken? Welke niet? In hoeverre sluiten gemaakte afspraken in het zorgleefplan aan op wat voor uw naaste van belang is?</i>
Interview guide voor bewoners met dementie	
Topics	Vragen
Openingsvraag	Hoe gaat het nu met u? <i>Om een idee te krijgen hoe gesprek gaat verlopen/gevoel te krijgen welke kant op te gaan.</i>
Zorgleef- en behandelplan	Wat is belangrijk in uw leven? <i>Waarom is dit belangrijk?</i> Wat moeten de zusters over u weten als ze u helpen? <i>Waarom is het belangrijk dat de zusters dit weten?</i>
Gezamenlijke besluitvorming	Hoe vindt u het om hier te wonen? <i>Wat vindt u fijn? Wat vindt u minder fijn? Wat zal beter kunnen?</i>

Table 2 Characteristics of the participants interviewed

Resident number	Interview resident (a)	Interview caregiver (b)	Stage of dementia *	Time since diagnosis ^a	Time living in nursing home ^a
1	1a		B	18	19
2	2a	2b	B	9	7
3	3a	3b	M	19	13
4	4a	4b	M	16	14
5	5a	5b	AD	48	25
6		6b	B	12	13
7		7b1 7b2	AD	23	20

B= beginning stage of the dementia; M= middle stage of the dementia; Ad= advanced stage of the dementia

* Judgment by physician

^a In months

Table 3 Quotes

Number	Category / codes	Quotes
		Theme 1: experiences with the multidisciplinary consultation
	<i>Moment to exchange knowledge</i>	
Q1	Space for questions	"Yes, if I come there the professionals are all present, and yes, there is space to ask questions I have at that moment, or things that are important to me." (Caregiver)
Q2	Changing experiences	"So then really, yes, then I will be asked about what my experiences are, and of course the nurses see my mother more often than I do, so then, then we exchange my experiences, the experiences of the nurses and, yes, also if I still have certain ideas for things to be addressed or solved." (Caregiver)
Q3	Discussing state of affairs	"So if you are at the multidisciplinary consultation and they tell the state of affairs and things that not go smoothly, then yes, then that is correct." (Caregiver)
Q4	Unclear use of jargon	"Then they told me we describe it that way in the plan. I really do not know what they called it, there were a few things of which I thought what is this? But I do know that I thought why do they mention this that way." (Caregiver)
	<i>Focus on medical topics</i>	
Q5	Medical topics	"And what I really liked, and I discussed that topic in the multidisciplinary consultation, that they reduced his medication use. I thought he was addicted to that medication, but they reduced that in a neat way, so that is fine." (Caregiver)
Q6		"Yes, it was about the weight, they keep a close eye on that. And the physician told somethings about her physical functioning, so those topics were addressed." (Caregiver)
Q7	Activities	"Well, as family we tell them involve her in activities. It took a while before they realised that my mother really likes activities and that she can do it too." (Caregiver)
Q8	Mood/depression	"However, they regularly look at the depression of my mother and we discuss this matter. So they check how she feels about it." (Caregiver)
Q9	Loss of loved ones	"So we discussed the grieving process of my mother with the psychologist. We got a little deeper in to this process and the things my mother went through and how she feels about this." (Caregiver)
	<i>Making decisions</i>	
Q10	Weighing advantages and disadvantages	"Of course there is response from our side, yes, for example with the eating and drinking. Than they told why she always drinks (brand of drink) and they indicate that they tried something else what is not working at the moment. So it is good to know they really tried and explained why it did not work, but that we have to choose the best of two evil. I fully understand this opinion." (Caregiver)

Q11	Decisions in dialogue	“Yes... I am aware of that, with that, uh, yes, they would ask my opinion, so yes, that is fine... The last time we discussed the reduction of medication before the consultation, and they did what they told me they would do. And the next time they told me what the amount of medication was at this time, so that is fine.” (Caregiver)
Q12		“Yes, I mean they change her medication and I have not been notified and I think that is a very strange situation. I think, I do not know how, but the information did not come through.” (Caregiver)
	<i>Limited time for optimal discussion</i>	
Q13	Discuss care- and treatment plan	“Actually, there is little change in the care- and treatment plan of my father. It is really, we will go through the plan and we speak about things that have been changed, for instance the use of bed rails, other than that there are no changes. Yes, we walk through the plan.” (Caregiver)
Q14	Time is limited	“You are time-bound during a multidisciplinary consultation, before you know, the next caregiver is present.” (Caregiver)
Q15	Lack of depth	“And then I leave the multidisciplinary consultation without the more comprehensive findings of the physician or information about her dementia from the psychologist. And then I think, we discussed everything but not in depth like you could do in the multidisciplinary consultation.” (Caregiver)
Q16	Lack of structure	“But because we get so much space as family I do miss a bit of structure. And there is a chairwoman, but I expect that we are going around, first the physician, the dietician, the first responsible nurse, you know. But then I experience a lack of structure.” (Caregiver)
Q17	In the corridors	“Than we discuss things at the ward and they tell me they will arrange it. Like with the laundry, that was a little clumsy so we made appointments to change it. And that also applies to a lot of other things.” (Caregiver)
	<i>Role first contact person</i>	
Q18	Know parent better than anyone else	“As caregiver... Uh, yes, quite important because I know my mother in a different way than the nurses know her for about a half year. I took care of her for six years, she is my mother, I have known her my whole life.” (Caregiver)
Q19	Reading care- and treatment plan and dossier	“It is all right, you know, I already saw the plan on paper, it is all right, sometimes the physician adds some information. And I always read the plan.” (Caregiver)
Q20		“So I always keep a close eye on the dossier, what is reported by the nurses and if I have to react on something.” (Caregiver)
Q21	Indicating boundaries	“Yes, about my role in the consultation, important affairs are being discussed and I can tell them about certain boundaries/limits on behalf of my sister and me. So what is the limit, like how we want the care to be provided but also what we no longer want.” (Caregiver)

		Theme 2: values/preferences in relation to care- and treatment plan
	<i>Values of residents/caregivers</i>	
Q22	Maintaining own direction	Resident: "I do not know what is in my closet, I cannot open that closet because it is locked." Caregiver: "I thought we agreed you could choose your clothes together with the nurse. That is also on the form on your closet, choose your clothes with the nurse every morning." (Resident)
Q23	Maintaining freedom	"Yes, I brought her mobility scooter so she could leave the ward and she can go in and around the nursing home. I took responsibility for that because her freedom is really important to her." (Caregiver)
Q24	Cosiness	Researcher: "I think you are fond of cosiness?" Resident: "Yes I am. The more visits I get, the better." (Resident)
Q25		Researcher: "To what extend are the values we discussed before, eating, cosiness, aligned with the plan?" Caregiver: "Well, they cannot improve the food, you know. That is a fact, you know, they cannot change anything about it. And about the other values, what they say or promise always happens. Perhaps because we discussed them before." (Caregiver)
Q26	Respect	"Yes, they approach her respectful, they call her the way she wants to. And I think that is really important to her." (Caregiver)
Q27	Privacy	Resident: "Yes, that is hard, because you have not got any privacy. No privacy at all." Researcher: "So the loss of privacy is a disadvantage of living in a nursing home with other people?" Resident: "Yes, they took my privacy, my privacy is gone." (Resident)
Q28	Independency	"Of course, you are your own boss and that is not the case right now. Now you are going like a child. Oh, where are the keys, oh where can I find this, oh that is true, oh at what time are we going to eat? Did you hear the news, no, because they turned it off, how nice, right?" (Resident)
Q29	Misunderstanding appointment	"Last time one nurse told me I could not shower on a Thursday because that was not agreed. So I told her I would like to shower and she said all right then." (Resident)
	<i>Preferences to get through the day</i>	
Q30	Going outside	"Yes, yes, I will go outside for a walk almost every day. But then, when this increased, I used to walk al lot more and further away, you know. But I refrained myself because I got lost several time." (Resident)
Q31	Listening and experiencing music	"Music, lovely. That is the most important thing." (Resident)
Q32	Playing games	"So I talked about playing games, especially with cards, with the first responsible nurse when we were discussing the care- and treatment plan. The nurse told me that my mother is great in playing games and she is a fast learner when it comes to new card games." (Caregiver)

	<i>Habits based on life story</i>	
Q33	Social contacts	"The more visitors I get, the better. Last time my room was completely full with people. Completely full with people how wanted to visit me. So I asked them if they could distribute their visits the next time." (Resident)
Q34	Children/family	"Yes, family was always really important and it still is. The cosiness about being together with family on Sundays at my parents' house, eating with each other. He was a great supporter of those days." (Caregiver)
Q35	Being important to someone	"But she always did a lot and she is missing that right now. It was very important to her that she was important to one another, that she added value in someone else's life." (Caregiver)
Q36	Needlework/creative activities	"Researcher: Did you used to decorate everything during Christmas and Easter?" Resident: "Yes, I always made a table with stuff on it." Researcher: "So you are a creative person?" Resident: "Yes, I love to do that kind of stuff, yes. But this table is created by my niece." (Resident)
Q37	Eating	"The food is good; I don't have to say anything about that. This afternoon we eat red cabbage and it was prepared the old-fashioned way." (Resident)
	<i>Perceived value care- and treatment plan</i>	
Q38	Plan not up-to-date	"So at the end, the essential appointments about the medication are included, but I expected that these appointments were already included when we went to discuss the plan." (Caregiver)
Q39	Essential things are missing	"It were just three, four things, but it were essential things that I was missing in the care- and treatment plan." (Caregiver)
Q40	Important values and preferences are missing	"Caregiver: And the way she is addressed is also important, and the nurses call her the way she wants. Researcher: And is this described in her plan? Caregiver: No, that is not described in the plan." (Caregiver)
Q41	Values and preference caregiver are mentioned in the plan	"So things are described, that he, but that are more my things than his things. I think taking a shower or going to the toilet on time are important things. And my father is not seeing those things as important." (Caregiver)
Q42	CTP is formality	"I think the care- and treatment plan is a formality. I do not see the added value; I only think having a plan is required." (Caregiver)