The perceptions, needs and preferences of informal caregivers of nursing home residents with dementia regarding physical therapy: a qualitative study

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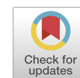

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A B S T R A C T

Introduction: Informal caregivers often support nursing home residents with dementia in making therapeutic decisions. We explored the perceptions, needs and preferences of informal caregivers of nursing home residents with dementia regarding physical therapy.
Method: We conducted eleven semi-structured interviews. Thematic analysis was used.
Results: Five themes emerged: 1) visibility and familiarity; 2) communication; 3) aim and content; 4) dosage and location; 5) level of expertise and the role of the physical therapist within the interdisciplinary team. Informal caregivers' perceptions of physical therapy included a lack of visibility and familiarity. They needed more communication, and empathic communication skills of the physical therapists. Preferences included physical therapy to be enjoyable, accessible and tailored to the needs of the resident.
Conclusion: Physical therapists need to involve informal caregivers in physical therapy care. Implementing shared decision-making will help to get informal caregivers more involved, but has yet to be studied in this setting.

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Introduction

With the aging of the population, the global demand for long-term care institutions such as nursing homes increases simultaneously.[1] It is estimated that 84% of nursing home residents have dementia.[2] Apart from cognitive and communicative problems,[3,4] many nursing home residents with dementia have physical disabilities, including reduced muscle strength,[5–7] decreased mobility,[5,6,8] an increased risk of falling[5,7–9] and limitations in Activities of Daily Living (ADL).[5,7,10]

Residents in nursing homes depend on interdisciplinary care in which physical therapists, nursing staff, physicians, occupational therapists, and other care providers work closely together in order to treat the problems caused by physical disabilities. For example, an estimated 69% of Dutch nursing home residents receive physical therapy.[11] According to a systematic review performed in 2019, this is noticeably more than other high-income countries, where on average 14% of the nursing home residents receive physical therapy.[12] In the Netherlands, most nursing homes have separate wards for long-term physical care (somatic wards), and for residents who receive long-term psychogeriatric care (psycho-geriatric wards). A previous study has shown that residents residing on a psycho-geriatric ward are less likely to receive physical therapy than residents residing on a somatic ward.[11]

Given the problems in cognitive functioning and communication, informal caregivers often support nursing home residents with dementia in making therapeutic decisions.[13,14] For this reason, healthcare professionals can collaborate with informal caregivers or resident representatives if the resident is unable to discuss therapeutic matters. Currently, little is known about the perceptions, needs and preferences of informal caregivers of nursing home residents regarding physical therapy. One study explored the views of informal caregivers of nursing home residents regarding a physical therapist-led exercise intervention.[15] The results indicated that family caregivers who understand the benefits of physical exercise have a more

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positive attitude towards physical exercise. Another study found that informal caregivers of nursing home residents with dementia often feel excluded and isolated, which can result in dissatisfaction with the provided care.[16] Regarding healthcare professionals, findings indicate that they do recognize the importance of working in partnership with informal caregivers, but have difficulties putting this into practice.[17]

Improving the relationship between the interdisciplinary team and informal caregivers can potentially reduce conflict, reduce work pressure and improve staff attitudes towards informal caregivers.[16] Furthermore, involvement of informal caregivers in nursing homes can positively affect the resident's well-being.[18] Optimized collaboration between family caregivers and physical therapists has previously been proven beneficial for older people and their families in a Transition Care setting.[19]

It is important to gain insight in the perceptions, needs and preferences of informal caregivers.[20,21] This can lead to a better involvement of the informal caregivers and may benefit the treatment of nursing home residents with dementia. Therefore, the aim of this study is to explore the perceptions, needs and preferences of informal caregivers of nursing home residents with dementia regarding physical therapy.

Method

Design of the study

We performed a descriptive, qualitative study with semi-structured interviews. Within the context of this study, we defined *perceptions* as a personal and subjective way of viewing a topic.[22] A *need* refers to an implicit, communicated or perceived state of deprivation,[23] and a *preference* is defined as a wish or desire, but is under no circumstances absolutely necessary.[24] The consolidated criteria for reporting qualitative research (COREQ) were used for the reporting of this study.[25]

Ethical aspects

In the Netherlands, only scientific studies in which participants are imposed to interventions or restrictions require approval of an ethics review board, according to the Medical Research Involving Human Subjects Act (Wet medisch-wetenschappelijk onderzoek (WMO)).[26] Approval to undertake this study was provided by the local research committee of the participating nursing home organization. This study was conducted according to the principles of the Declaration of Helsinki (World Medical Association, 2000). All study data were handled confidentially and in accordance with the General Data Protection Regulation (GDPR).[27] All participants gave their written informed consent.

Setting

The study was conducted in 2021 and took place in four nursing homes that are part of the healthcare organization “Kennemerhart”, located in and around the urban area of the Dutch city Haarlem. The selected homes accommodate between 60 and 110 residents. The long-term care wards for residents with dementia are similar in all nursing homes, and all have the characteristics of a small, domestic-style care setting. Every ward has multiple households. Each household is shared with a maximum of ten residents. All nursing homes hold personal care-plan meetings twice a year in which care and therapeutic topics are discussed. Informal caregivers can participate in care-plan meetings at two of the four locations. In the other two locations the care-plan meetings are first held with the medical staff, and the results of this meeting are later discussed between informal caregivers, a licensed nurse and the physician in charge. In all nursing homes, authorized informal caregivers can access the electronic medical record in which the physical therapists report.

At the time the study was conducted, seven physical therapists worked a combined total of 98 hours per week, delivering care to 184 residents on eleven long-term wards (on average 0.53 hours per resident per week). The physical therapists evaluated basic physical functions and the risk of falling of every new resident. This evaluation is used to decide if the resident needs physical therapy treatment. The content of physical therapy treatment in the nursing homes was comparable to other Dutch nursing homes and predominantly consisted of exercise therapy.[28] Besides exercise therapy, physical therapists provided (lymph drainage) massage, relaxation exercises and consultations on pain and mobility problems. All physical therapy sessions or consultations were individual, no group sessions were conducted. Apart from interventions aimed at the resident, physical therapists advised staff and informal caregivers of residents on a variety of health-related issues such as fall-prevention, behavioral and psychological symptoms in dementia, mobility in ADL and transfer-techniques during daily care.[28]

Participants

Potential participants for the study were informal caregivers related to residents with dementia living in the four previously described nursing homes. The seven physical therapists working in the nursing homes provided a list of informal caregivers of nursing home residents with dementia who were living in the nursing home between March 31st and May 10th, 2021. We invited the informal caregivers by email to participate in the study, in accordance with the terms and conditions for scientific research in Dutch nursing home care.[29] The invitations included information about the study and a hyperlink to an online questionnaire (which was used to map the characteristics of the participants) in order to screen for eligibility. Informal caregivers were eligible if they: 1) Were involved in the decision-making process regarding the health and wellbeing of the resident; 2) Did not have mental or physical problems that could impede with the interview; 3) Spoke Dutch. If no response was obtained after the first e-mail, a maximum of two reminder e-mails were sent. Potential participants were ensured that their participation in the study was voluntary and that participation or non-participation would not affect the care for their relative.

Data collection

The interviews were conducted by four female physical therapy students (MG/ AK/ AL/ SM) who were supervised by two senior researchers who are experienced in qualitative research (FL/ AH). We created an interview guide that covered topics of interest in line with the study. The interview guide consisted of six topics (physical therapy treatments, expertise, collaboration between the physical therapist and the informal caregiver, level of support, communication, role of the physical therapist in the interdisciplinary team). The interview guide was pilot tested with the first author before use, but no major changes were made (Appendix 1). The semi-structured interviews took place between April 15th and May 18th, 2021 and were conducted digitally.

During each interview three persons were present: the interviewer, the observer and the participant. The interviewer conducted the interview, while the observer checked for completeness. The Jitsi-meet website (https://meet.jit.si) was used to digitally communicate with participants and audio-recordings were made with the Apple recording program OBS Studio 26.1.0 (Open Broadcast Software Studio Contributors, San Francisco, United States of America). The recordings were temporarily stored on a password secured

Google OneDrive and were destroyed after transcription and analysis. No personal information from participants was visible in the transcripts of the interviews.

There was no existing personal or other relationship between the students and the participants prior to this study. Previous research has shown that data saturation can occur between six and twelve interviews.[30] In order to achieve data saturation, we aimed to conduct at least ten interviews, and to continue with the interviews until no new topics were raised on two consecutive interviews. No unforeseen problems arose during the interviews, therefore none of the interviews had to be repeated.

Data analysis

We used descriptive statistics to present basic characteristics of informal caregivers.

Regarding the interviews, the audio files of all interviews were transcribed verbatim. Transcripts were not returned to the participants for correction. The transcripts were qualitatively analyzed by an alternating team of two researchers (AL/ MG/ AK/ SM) according to the guidelines for qualitative research in healthcare by Rapport et al.[31] We used thematic analysis, in which the researchers select and code interesting features of the data and later collate codes into potential themes.[32] An alternating set of two researchers (AL/ MG/ AK/ SM) independently performed all coding using ATLAS.ti web (https://atlasti.com). Discrepancies in codes between researchers were discussed in order to reach consensus. Codes with comparable content were merged into minor themes, and minor themes with comparable content were subsequently merged into major themes. The contents of the major themes were similar to the contents of the interview guide, but after the data collection the contents were reorganized. During the data analysis we made separate divisions of the *needs* and *preferences.* The combined analysis was then reviewed by the principal investigator to ensure accuracy and clarity of the themes and subthemes.

Results

Participants

A total of 184 informal caregivers received the invitation to participate in the study. Eleven caregivers (6%) explicitly declined to participate, whereas 160 (87%) informal caregivers did not respond to the first email and reminder emails. Ultimately, thirteen caregivers agreed to participate (response rate 7%) (Fig. 1). The participant characteristics are described in Table 1. As Table 1 shows, the majority of the respondents had a daughter/son relationship with the resident (84.6% of the sample) and most caregivers were female (69.2%).

After eleven interviews no new issues were raised and the researchers concluded that data saturation had occurred. The interviews lasted between 30 and 58 minutes (on average 43 minutes). The results of the six topics were merged and divided into five major themes: 1) visibility and familiarity; 2) communication; 3) aim and content; 4) dosage and location; and 5) level of expertise and the role of the physical therapist within the interdisciplinary team. The major themes, the minor themes, the condensed results categorized in perceptions, needs and preferences and selected participant's quotes are presented in Table 2.

Theme 1: Visibility and familiarity

Perceptions

Regarding perceptions, most informal caregivers indicated that they knew little about physical therapy in the nursing home. According to them, this was partly because they had no medical background themselves, but also because they were not informed about the activities of a physical therapist in the nursing home. Some caregivers indicated that they were unaware that physical therapy was provided by the nursing home. Only few had met the treating physical therapist in person.

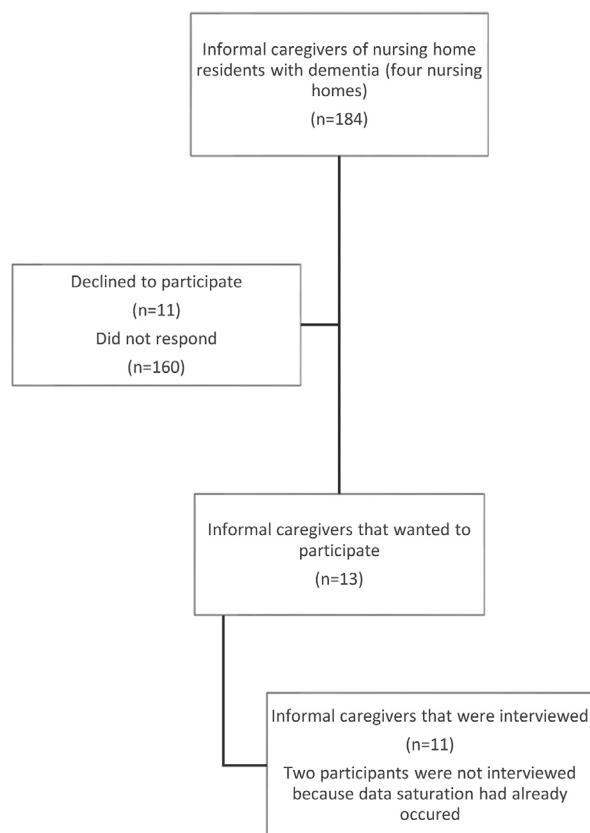

Fig. 1. Flowchart of inclusion of participants in the study.

Table 1
Characteristics of informal caregivers of residents of nursing homes with dementia, participating in a qualitative study on nursing home physical therapy (n=13)

		n =13 (%)
Age	46-55 years	2 (15.4)
	56-65 years	5 (38.5)
	66-75 years	6 (46.2)
Gender	Male	4 (30.8)
	Female	9 (69.2)
	Other	-
Educational level *	Low	2 (15.4)
	Middle	4 (30.8)
	High	7 (53.8)
Nationality	Dutch	13 (100)
Duration of provision of informal care	1-5 years	5 (38.5)
	> 5 years	8 (61.5)
Relationship to resident	Daughter/son	11 (84.6)
	Aunt	1 (7.7)
	Daughter/son in law	1 (7.7)
Years of resident living in nursing home	< 1 year	4 (30.8)
	1-3 years	6 (46.2)
	> 3 years	3 (23.1)
Weekly hours as informal caregiver	< 10 hours	8 (61.5)
	10-20 hours	5 (38.5)
How demanding is being an informal caregiver?	Lightly demanding	7 (53.8)
	Moderately demanding	5 (38.5)
	Very demanding	1 (7.7)

*Low: Up to secondary school; *Middle*: associate's degree; *High:* bachelor's degree, university degree or higher.

Table 2
Major themes, minor themes and selected participant's quotes after the analysis of eleven interviews with informal caregivers of nursing homes residents with dementia

Major theme	Minor theme	Results Perceptions	Needs	Preferences	Participants quotes
Visibility and familiarity with physical therapy in the nursing home	Understanding of physical therapy	Limited knowledge about physical therapy in the nursing home.	More frequent information about physical therapy and their activities.	More insight in the decision-making process of physical therapists.	*“I don’t have enough understanding about physical therapy, because I do not know what they [the physical therapists] do. Since my father has dementia, I can’t always rely on him to tell me.” (Informal caregiver (I) 4) (Perceptions)*
	Information provision on physical therapy	Lack of information from the physical therapists or the nursing home staff about physical therapy.	More frequent information about the progress of the treatment and the used interventions.		*“Occasionally an open day or introduction day is held in nursing homes [. . .] it might be interesting for the physical therapists to present themselves as well." (I 13) (Needs)*
	Visibility of physical therapists	Lack of visibility; Not seen the treating physical therapist personally.			*"I don't see any physical therapists. Maybe there's someone walking around in uniform, but I don't know what their function is. I don’t know whether he or she belongs to the nursing staff or to physical therapy.” (I5) (Perceptions)*
Communication between informal caregivers and physical therapists	Moments of communication	Little or no communication with the physical therapists of the nursing home.	More communication with physical therapists.		*“I don’t have prejudice against the physical therapists. In my experience they [the physical therapists] are all clear and empathic. But at the moment I do miss communication" (I 6) (Needs)*
	Care plan meeting	Different experiences whether physical therapy was discussed at the care-plan meetings.	Discuss physical therapy matters		*“In my opinion, a physical therapist should be present at every care-plan meeting” (I 4) (Needs)*
	Ways of communication		Understandable language, no medical jargon	The digital patient file can be used to communicate.	*“If I could read updates, for example a monthly update, in the digital patient file, that would be sufficient for me” (I 8) (Needs), “I prefer face-to-face communication, in a way that they will take time for a conversation. But nowadays digital meetings have been a good alternative” (I 6) (Preferences)*
	Subjects of discussion		All physical therapy matters.	Physical therapy appointments are visible, to help plan a visit.	*“I wish to be kept informed about whether something is or is not going well. Or to discuss what is important to me, because my father usually does not indicate it himself.” (I 3) (Needs)*
Aim and content of physical therapy	Goal and contents of physical therapy	Physical therapy is aimed at preserving the physical functioning of the resident, mostly by exercise training.	Tailored to the individual needs of the resident; Advice on how to stay healthy themselves; Exercise needs to be enjoyable.	Improving posture and maintaining a healthy day-night rhythm	*“I envision the physical therapist analyses the mobility of the resident and where necessary, tries to improve it” (I 1) (Perceptions), “I personally find it incredibly hard to push a wheelchair. A physical therapist might be able to give me tips and tricks on [how to do] that" (I 1) (Needs), “I think regular exercise is what is best for the residents, to try to decelerate the process of Alzheimer’s and to also maintain their day-night rhythm” (I 9) (Preferences)*
	Individual or group therapy		Individual and group therapy, suited to the needs of the resident.		*“I think it can be very stimulating for a resident to attend therapy with multiple residents. Having group therapy and seeing others exercise can have a stimulating effect.” (I 1) (Needs)*
	Tailoring to the resident		Including elements of sports and games.	E-health, such as a virtual bike trainer	*"Cycling by means of a digital home trainer through the neighborhood she grew up. Of course, that’s fantastic! Thus, you have a combination of physical and cognitive exercise” (I 9) (Preferences)*
Dosage and location of physical therapy	Duration of the treatment	About 30 minutes.	Tailored to the individual needs and capacities.		*“Because the attention span of elderly people is not that long, I think fifteen minutes of exercise is enough for them.” (I 4) (Needs)*
	Frequency	Once or twice a week.		At least once a week exercise, even if it is not guided by a physical therapist.	*“It depends on the nature of the treatment. If it is a severe injury, I assume treatment could take place twice or three times a week. But as I said, the frequency depends on the necessity of the treatment.” (I 11) (Perceptions)*

(*continued on next page*)

Table 2 (*Continued*)

Major theme	Minor theme	Results Perceptions	Needs	Preferences	Participants quotes
	Location of the treatment	The apartment of the resident, exercise room or outside.	When necessary, a low stimulus environment.	When weather allows, physical therapy in the outdoors.	*"I never met a person who doesn't like being outside. By being outside people are stimulated to do something which they may find difficult, but will try it anyway." (I9) (Preferences)*
Level of expertise and the role of the physical therapist within the interdisciplinary team	Level of expertise	A Bachelor's degree of physical therapy	Empathy for the residents with dementia; Communicate in a calm and friendly manner.		*"I assume therapists have both affinity and training on the subject of geriatric care and related topics" (I1) (Perceptions)*
	Interdisciplinary care	The physical therapist discusses physical functioning with other healthcare professionals.	Discuss interdisciplinary treatments that influence the physical functioning of the resident.		*"I would like direct involvement of the physical therapist, so that the physical therapist can discuss his observation immediately within the multidisciplinary team" (I10) (Needs)*
	Supplementary courses			Courses for a fitting attitude to nursing home residents with dementia.	*"It's not necessarily having a degree in geriatrics; it mainly has to do with the conduct or attitude towards residents" (I2) (Preferences)*

Needs

Nearly all informal caregivers mentioned a need for more frequent information about physical therapy. For example, they would like to be informed when the physical therapist starts, stops or modifies the treatment. Furthermore, they expressed the need to have more information about the progress of the treatment and which interventions are used to achieve healthcare goals.

Preferences

Some informal caregivers mentioned that gaining more insight in the decision-making process of the physical therapist could lead to a higher satisfaction about physical therapy.

Theme 2: Communication

Perceptions

Most participants indicated that there had been little or no communication with the physical therapist of the nursing home. One caregiver stated that he/she was informed about physical therapy for the resident during a periodic care-plan meeting. Other informal caregivers mentioned that they had attended periodic care-plan meetings, but these meetings were without the presence of a physical therapist or without discussing physical therapy.

Needs

Nearly all informal caregivers expressed the need for more communication with the physical therapist. They also indicated that they needed opportunities to discuss physical therapy and physical therapy treatment matters. According to some informal caregivers, these matters could be discussed during the periodic care-plan meeting.

Preferences

Some participants preferred to exchange information by use of the electronic medical record. However, the current way of reporting by physical therapists was also perceived as insufficient, brief and with medical jargon which is difficult to understand. Regarding the frequency of reporting in the record, some informal caregivers preferred a report after every physical therapy session, while one report every two or three months would suffice for others. Some informal caregivers also requested that the physical therapy appointments would be visible to the caregivers, to help plan their visits to the resident.

Theme 3: Aim and content

Perceptions

Most informal caregivers perceived that physical therapy is aimed at preserving the resident's physical functioning. They assumed that the treatment would consist of various modalities, of which the following were mentioned: strength training; exercises related to everyday life movements; endurance training; gait training with attention for walking aids; breathing therapy; relaxation therapy and massage.

Needs

All informal caregivers considered it of importance that treatment was tailored to the individual's needs. Moreover, they thought that physical therapy should be offered in both groups and individually. The needs of most caregivers regarding the content of physical therapy were similar to the abovementioned expressed perceptions of

current therapy, but multiple informal caregivers suggested to include elements of sports and games in the therapy. They speculated that it would make the therapy more accessible and more enjoyable. Regarding the aim of the treatment, multiple informal caregivers expressed a need that physical therapy attends the posture of the residents. They expected that an improved posture would reduce the risk of falling. Besides treatment aimed at the resident, a need for interventions directed at informal caregivers was expressed. For example, one informal caregiver wanted advice on how to push a wheelchair without inflicting harm to her/himself (see quote in Table 2).

Preferences

Some caregivers indicated a preference to improve the day-night rhythm of the residents by reducing sedentary behavior during the day. They specified that stimulating residents to be more active during the day is not the responsibility of the physical therapist, but they suggested that the physical therapist can make an interdisciplinary strategy to reduce sedentary behavior. To make physical therapy more accessible, some participants suggested the use of e-health, for example a virtual bike ride.

Theme 4: Dosage and location

Perceptions

Most informal caregivers expected a physical therapy session to last for around 30 minutes, as this is the duration they experienced when receiving physical therapy themselves. Some caregivers expected the treatment to last closer to fifteen minutes. For them a fifteen-minute treatment duration would be in line with a diminished attention span which is common in nursing home residents with dementia (see quote in Table 2). Most caregivers thought that physical therapy treatment took place once or twice a week. Regarding the location of the treatment, informal caregivers had the perception that treatment takes place in the residents' apartment, in the exercise room of the nursing home, or outside.

Needs

All participants expressed the need for a sufficiently long treatment duration, in order to guarantee the quality of the treatment. The duration of the treatment should be tailored to the individual's situation, with a possible duration ranging from fifteen minutes to one hour. Regarding location, some informal caregivers mentioned that, if necessary, a low-stimulus environment should be provided.

Preferences

Multiple informal caregivers stated their preference for a weekly program that contains at least some form of physical exercise. They also mentioned that exercise interventions do not always have to be guided by a physical therapist. Exercise interventions could be given by nursing home assistants, and a physical therapist could help design the exercise intervention to ensure quality and effectiveness. Regarding location, several informal caregivers preferred that physical therapy occasionally will be held outside, when weather allows.

Theme 5: Level of expertise and the role of the physical therapist within the interdisciplinary team

Perceptions

Most participants perceived that besides holding a bachelor's degree in physical therapy, the physical therapist would have additional competences in how to treat nursing home residents with dementia. Regarding the role of the physical therapist in the interdisciplinary team, most informal caregivers expected physical therapists to be concerned with the resident's physical functioning and to communicate with other professionals from other disciplines regarding topics such as mobility or balance.

Needs

Almost all informal caregivers thought it was important for the physical therapist to empathize with the residents, and to communicate in a calm and friendly manner. Not all informal caregivers considered it necessary for physical therapists to specialize in geriatrics or obtain a master's degree after completing the bachelors physical therapy degree.

Regarding the role in the interdisciplinary team, several informal caregivers indicated that physical therapists should inform other disciplines if their interventions interfere with the physical functioning of the nursing home resident. For example, if medication prescribed by the geriatrician makes the resident unstable and increases their likelihood of falling, the physical therapists are expected to communicate with the involved geriatrician and discuss the matter at hand.

Preferences

Regarding *preferences*, some informal caregivers in this study expressed the wish for physical therapists to follow additional courses aimed at creating a “fitting attitude and approach” to nursing home residents with dementia. By this they mean that physical therapists get taught on how to deal with the behavioral and communication disorders that can be present in residents with dementia.

Several years of work experience in geriatrics and creativity in treatment were considered as preferred characteristics for physical therapists.

Discussion

The perceptions, needs and preferences regarding physical therapy expressed by informal caregivers of nursing home residents with dementia were identified and then categorized into five major themes: 1) visibility and familiarity; 2) communication; 3) aim and content; 4) dosage and location; and 5) level of expertise and the role of the physical therapist in the interdisciplinary team.

The findings presented in the first two themes showed that the majority of the informal caregivers lacked knowledge about physical therapy in the nursing home, and had therefore difficulties providing perceptions on several topics. Furthermore, most informal caregivers experienced insufficient communication with physical therapists. International policies and previous research recommend the involvement of informal caregivers of people with dementia, and advise to make efforts to understand their needs.[20,21] Our findings support the need for informal caregivers to be involved and to be understood. Most studies about the involvement and needs of informal caregivers in the nursing home are about daily care.[33] Our study shows that working together with informal caregivers is not only necessary for nurses, who communicate more about daily care, but also for other healthcare professionals of the interdisciplinary team such as physical therapists. A possibility to involve and to understand informal caregivers is to implement shared decision-making. In shared decision-making, the healthcare professional and the patient and/or their informal caregiver make decisions together. It is a way of asking informal caregivers about their needs, and it can prevent disappointment or dissatisfaction about the outcome of a treatment.[21]

International differences in physical therapy provision could however influence the implementation of shared decision-making. The systematic review by Brett et al. demonstrated that massage,

electrotherapy and pressure ulcer management are common physical therapy treatments used in Australia and the US, respectively.[12] These are treatments that might involve less collaboration with informal caregivers than for example physical exercises, which are more common in the Netherlands and Europe.[12,28] Even though (physical therapy) treatments differ internationally, involving informal caregivers is a necessary task for all healthcare professionals who work with nursing home residents with dementia.[33,34]

Themes three, four and five address the needs of informal caregivers regarding the skills of physical therapists, the content of physical therapy and the location of treatment. Informal caregivers indicated that they need physical therapists to communicate with empathy, and that they prefer pleasure elements in physical therapy such as sports, games and outdoor therapy. These findings differ from a study from 2008, where informal caregivers of nursing home residents with dementia placed greater meaning in the functional use of an activity.[34] The difference in findings may be explained by the time when the study was conducted. In recent years there has been more attention to the quality of life and the needs of nursing home residents with dementia.[20,35,36] Informal caregivers could therefore also be more concerned about enjoyment and pleasure elements in activities than they were before. A recent review shows that bringing enjoyment to exercise interventions and making adequate use of communication skills does increase adherence to exercise in nursing home residents with dementia.[37] If physical therapists pay more attention to pleasure elements in exercise and effective communication, the adherence to exercise therapy can be higher and the intervention could be more effective.

A strength of our study is that, to our knowledge, this is the first study to explore the perceptions, needs and preferences of informal caregivers regarding the interdisciplinary team. Many studies have been conducted on the needs of informal caregivers regarding nursing home staff, but the needs regarding the interdisciplinary team have not been included.[33,35,40] The interdisciplinary team has a substantial role in the care for nursing home residents with dementia, and the needs of informal caregivers regarding the interdisciplinary team should not be overlooked. A second strength of our study is that by using the COREQ criteria for reporting, we were able to present our method, findings and implications in a comprehensive and complete way.

There are several limitations. Firstly, all informal caregivers were invited to participate, regardless of whether their relative had received physical therapy. This could mean that informal caregivers based their perceptions on physical therapy, that was not being provided. However, in this nursing home sample, all physical therapists are supposed to evaluate the physical functioning and risk of falling with every new resident and before every care-plan meeting. It is therefore not likely that the lack of communication experienced by informal caregivers is caused by a lack of opportunities for physical therapists to reach out to them. A second limitation concerns the generalizability of our findings. The geriatric health care system in the Netherlands is managed differently than in many other countries. A key difference is that nursing home staff includes, among others; physicians, physical therapists, occupational therapists, speech therapists and psychologists.[41] The way of health care and nursing home care management will likely influence the perceptions, needs and preferences of informal caregivers of nursing home residents with dementia. Furthermore, the informal caregivers that participated in our study were all Dutch and lived in an urban environment, and most of them have attended higher education. Previous studies have shown that demography, culture and the education level influence the needs of informal caregivers.[38,39] Exploring the needs of informal caregivers of healthcare professionals in other regions and countries could discover additional information not addressed in our study.

Taking the abovementioned strengths and limitations into account, this study brings the following implications for future practice:(1); Physical therapists and other healthcare professionals working with nursing home residents with dementia need to be more aware of the needs and preferences of the informal caregivers. This can be achieved by implementing shared decision-making. (2); Regarding the contents of the physical therapy, physical therapists should try to bring enjoyment in therapy, and utilize ways of communication that are appropriate for nursing home residents with dementia.

Future research could explore the collaboration preferences of informal caregivers, specifically with physical therapists working in nursing homes. Investigating the effect of shared decision-making and what kind of role informal caregivers prefer in collaboration with healthcare professionals can provide useful practical information.

Conclusion

Most informal caregivers lacked knowledge about the provision of physical therapy in the nursing home, and needed more communication. Informal caregivers need physical therapists to communicate calmly and with empathy with the nursing home residents. They preferred physical therapy to be enjoyable, accessible and tailored to the needs of the resident. Involving informal caregivers in the care of the residents is not only the responsibility of nurses or doctors, but of other members of the interdisciplinary team as well. Implementing shared decision-making is a way to involve informal caregivers, but has yet to be studied in the context of interdisciplinary care of nursing home residents with dementia.

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Appendix 1. Interview guide for the semi-structured interviews

TOPIC	Perceptions	Needs/Preferences
Physical therapy treatments	What is your perception of the current physical therapy treatments for nursing home residents with dementia? (In your perception, what kind of treatments are offered by physical therapy)	What do you need from physical therapists for the nursing home residents with dementia? What kind of treatments need to be provided by physical therapists according to you?
	What is your perception of the duration of one physical therapy session?	What duration do you need the physical therapy to be? (What are your desires regarding the duration of the physical therapy sessions)
	In your perception, is physical therapy offered in group sessions or in individual sessions?	What composition do you prefer for the physical therapy sessions (Individual/group/different)
	In your perception, how often do residents get physical therapy?	How often do you prefer physical therapy takes place (weekly)
	In your perception, what kind of goals or outcomes	Which goals or outcomes do you feel physical therapy should target?

(*continued*)

(*Continued*)

TOPIC	Perceptions	Needs/Preferences
	are targeted by physical therapy?	
	Where do you expect the physical therapy sessions take place?	In which place(s) do you want physical therapy to take place? It doesn't always have to be the same place, it could be multiple options.
	In your perception, do informal caregivers get informed about the status of the physical therapy of the resident?	In what extend do you need to be informed about the physical therapy of the resident? Could you elaborate?
Expertise	In your perception, what is the level of education of the physical therapists (bachelor or master) ?	What is your desired education level of the physical therapists? Could you elaborate?
	Do you perceive that the physical therapists have other qualifications regarding the treatment for the residents? Could you elaborate?	What other qualifications do you need from physical therapists? (courses, attitude, etc.)
	What are your perceptions regarding the empathy and compassion of the physical therapists towards the nursing home residents with dementia?	What are your needs regarding the empathy and compassion of the physical therapists towards the nursing home residents with dementia?
Collaboration between the physical therapist and the informal caregiver	How do you perceive the collaboration between physical therapist and the informal caregiver? According to you, what is the current state of collaboration of physical therapists and informal caregivers?	What do you need in the collaboration between physical therapists and informal caregivers? Could you elaborate?
	What is your perception about the current level of shared decision making? Currently, in what way do you perceive informal caregivers can influence physical therapy?	What are your needs regarding shared decision making?
Level of support	What are your expectations regarding getting supported by physical therapists? In your perceptions, do informal caregivers currently receive support from physical therapists?	What do you need regarding support from physical therapists?
	Currently, on what domains do informal caregivers receive support from physical therapists?	On what domains do you need or desire support from physical therapists?
Communication	What is your perception of the current communication between physical therapists and informal caregivers?	What do you prefer regarding the communication between physical therapists and informal caregivers?
	How often do you perceive physical therapists and caregivers currently communicate?	How often do you prefer or need physical therapists and informal caregivers communicate?
	According to your perception, what form of communication is currently used?	Which form of communication has your preference? (Multiple options, elaborate)
	In your perception, is there direct communication or indirect communication (As in through nurses, doctors, other staff	Could you elaborate on the preferred communication, direct or indirect?

(*continued*)

(*Continued*)

TOPIC	Perceptions	Needs/Preferences
	members but also by using patient files, notebooks in the resident's room)	
Role physical therapists in the interdisciplinary team	According to your perception, could you describe the role of the physical therapist in the interdisciplinary team?	What is your preferred role of the physical therapist in the interdisciplinary team?
	In your perception, what influence does the physical therapist have in the interdisciplinary team?	What influence do you need from the physical therapist in the interdisciplinary team? (Or in what way? Elaborate)
	In your perception, how is the physical therapist involved in the interdisciplinary team? (direct, or through the head nurse, other options?)	In what way do you want the physical therapist to be involved in the interdisciplinary team? (direct or indirect, other options)
Summary question		To what extend are you satisfied with your current experiences with physical therapy?
		Do you have any recommendations regarding physical therapy for nursing home residents with dementia?
		Would you like to address further topics?

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