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How do patient-informal caregiver dyads experience care and how do they define good care?

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How do patient-informal caregiver dyads experience care and how do they define good care?

How do professionals experience care and how do they define good care?

Methods

Study design

Dyads

- Qualitative study in a phenomenological–hermeneutical philosophy
- In-depth interviews

Data collection

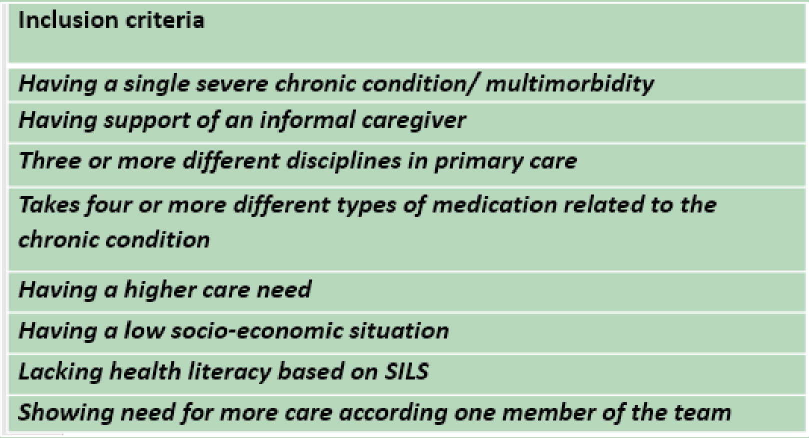
Dyads

- Interviews focussing on self-management (SM), interprofessional collaboration and integration (IPCI) and goal-oriented care (GOC)
- In total: 16 duo-interviews (ẋ = 1h16)
- Kick-off: ‘Tell me, what did your last week look like?’

Participants

Dyads

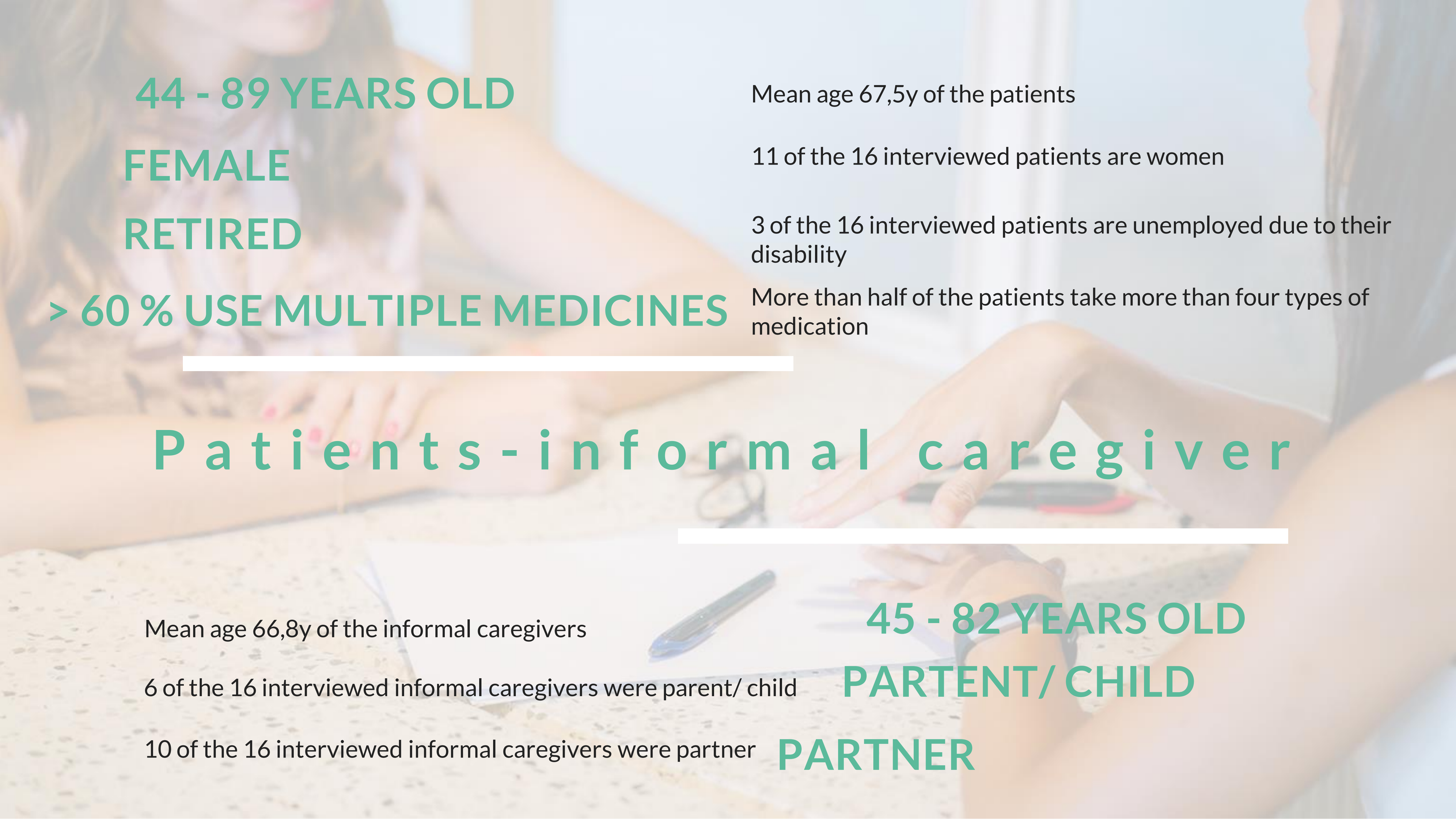
- Dyads: patients and their informal caregiver
- Maximum variation
- Recruitment: GPs as gatekeepers
- Inclusion criteria ~ Iglesias (2018)



Inclusion criteria
Having a single severe chronic condition/ multimorbidity
Having support of an informal caregiver
Three or more different disciplines in primary care
Takes four or more different types of medication related to the chronic condition
Having a higher care need
Having a low socio-economic situation
Lacking health literacy based on SILS
Showing need for more care according one member of the team

Participants

Inclusion criteria	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
Having a single severe chronic condition/ multimorbidity	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
Having support of an informal caregiver	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
Three or more different disciplines in primary care	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
Takes four or more different types of medication related to the chronic condition	X	X	X	X		X	X	X	X		X		X		X	
Having a higher care need					X		X	X			X			X		
Having a low socio-economic situation	X	X							X							
Lacking health literacy based on SILS			X							X		X				
Showing need for more care according one member of the team	X	X														X

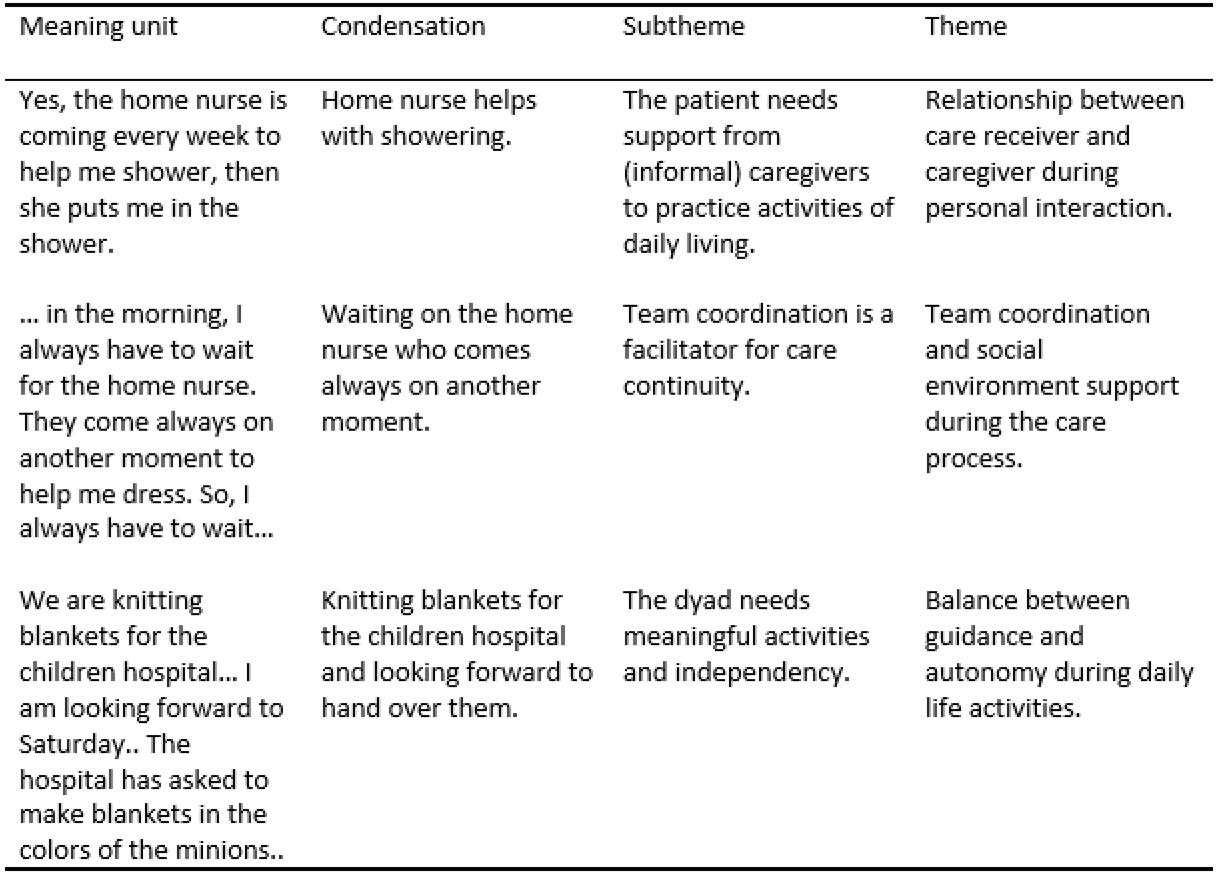


44 - 89 YEARS OLD	Mean age 67,5y of the patients
FEMALE	11 of the 16 interviewed patients are women
RETIRED	3 of the 16 interviewed patients are unemployed due to their disability
> 60 % USE MULTIPLE MEDICINES	More than half of the patients take more than four types of medication

Patients-informal caregiver

Mean age 66,8y of the informal caregivers	**45 - 82 YEARS OLD**
6 of the 16 interviewed informal caregivers were parent/ child	**PARTENT/ CHILD**
10 of the 16 interviewed informal caregivers were partner	**PARTNER**

Data analysis – Lindseth & Norberg (2004)



Meaning unit	Condensation	Subtheme	Theme
Yes, the home nurse is coming every week to help me shower, then she puts me in the shower.	Home nurse helps with showering.	The patient needs support from (informal) caregivers to practice activities of daily living.	Relationship between care receiver and caregiver during personal interaction.
… in the morning, I always have to wait for the home nurse. They come always on another moment to help me dress. So, I always have to wait…	Waiting on the home nurse who comes always on another moment.	Team coordination is a facilitator for care continuity.	Team coordination and social environment support during the care process.
We are knitting blankets for the children hospital… I am looking forward to Saturday.. The hospital has asked to make blankets in the colors of the minions..	Knitting blankets for the children hospital and looking forward to hand over them.	The dyad needs meaningful activities and independency.	Balance between guidance and autonomy during daily life activities.

Results

Naïve understanding – dyads

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Identification of themes

Autonomy to be in charge of health and welfare decisions.

Meaningful activities to create a fulfilling life.

Performance of essential activities supported by a team of (in)formal caregivers.

Supportive network to participate in society.

Practical and psychosocial support to manage meaningful and essential activities.

Balance between practical and emotional caregivers' skills.

Patient-provider dialogue to achieve an open communication.

Involvement to facilitate 'care-decision making'

Care coordination as part of care continuity.

Barriers to provide good care.

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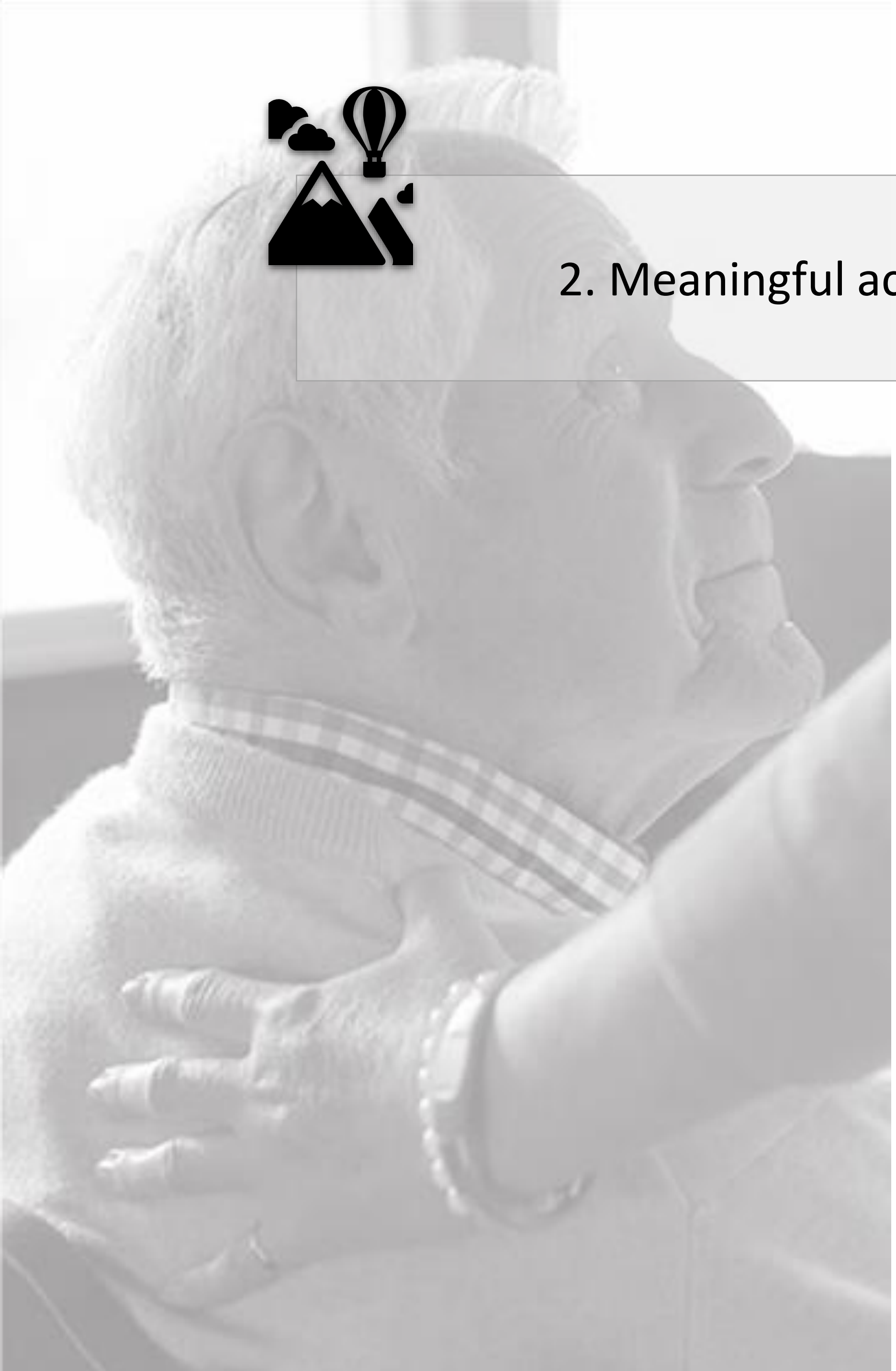
1. Autonomy to be in charge of health and welfare decisions.

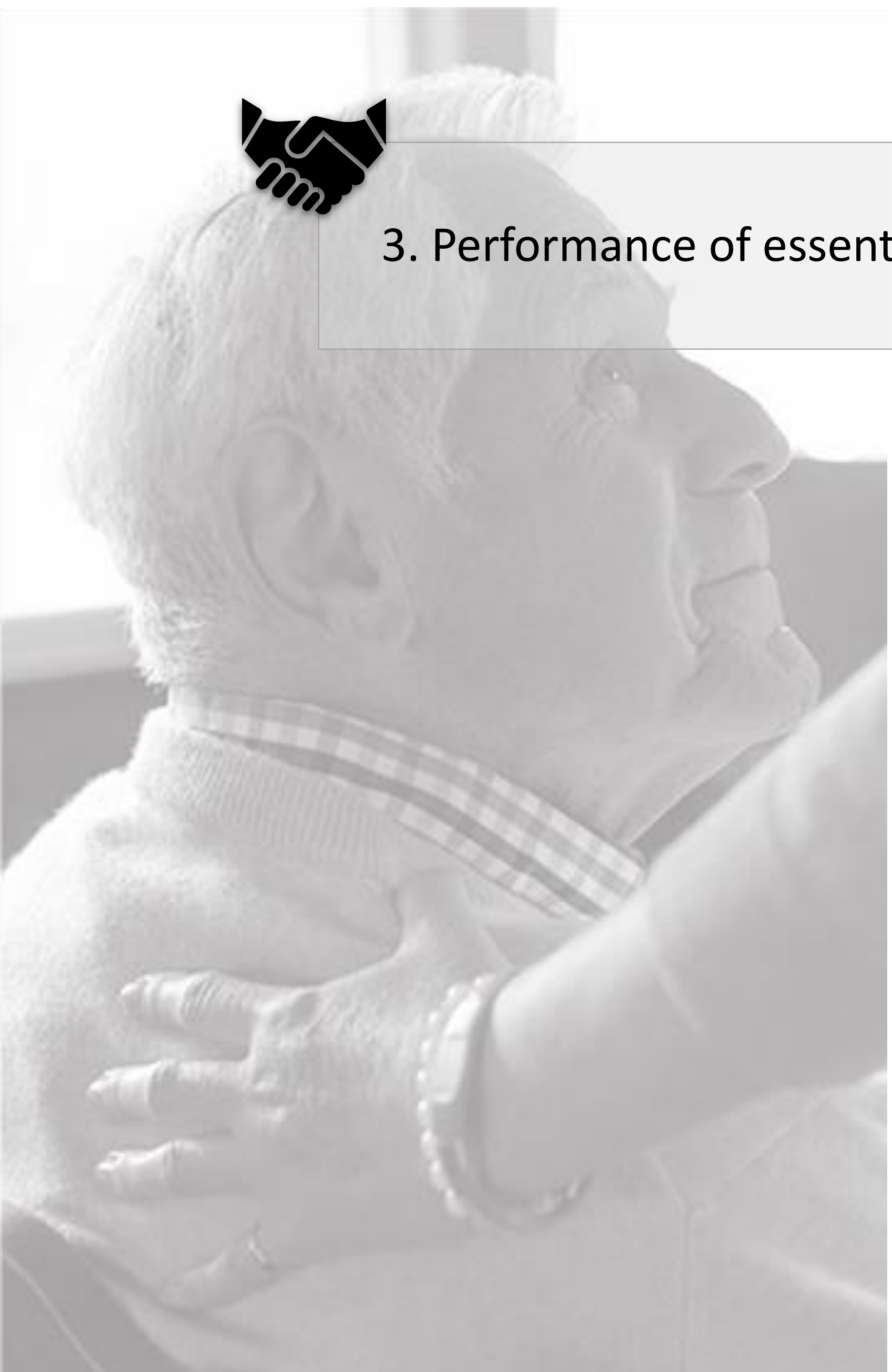
> *“I have always been someone who was independent, did everything myself, never asked for help. For me, it is a huge step to ask someone, my son or family, for help. Just putting my walking aid downstairs for a moment is very difficult. I feel my independence slipping away, I find it annoying. I try to do all that myself, but then I am so tired.”*



2. Meaningful activities to create a fulfilling life.

“We are still rearranging. Now I have to cook in several times while I used to do that in once… I also do some woodwork for a few hours in the hobby room and do some gardening. We rearrange ourselves to the things I am still able to do.”

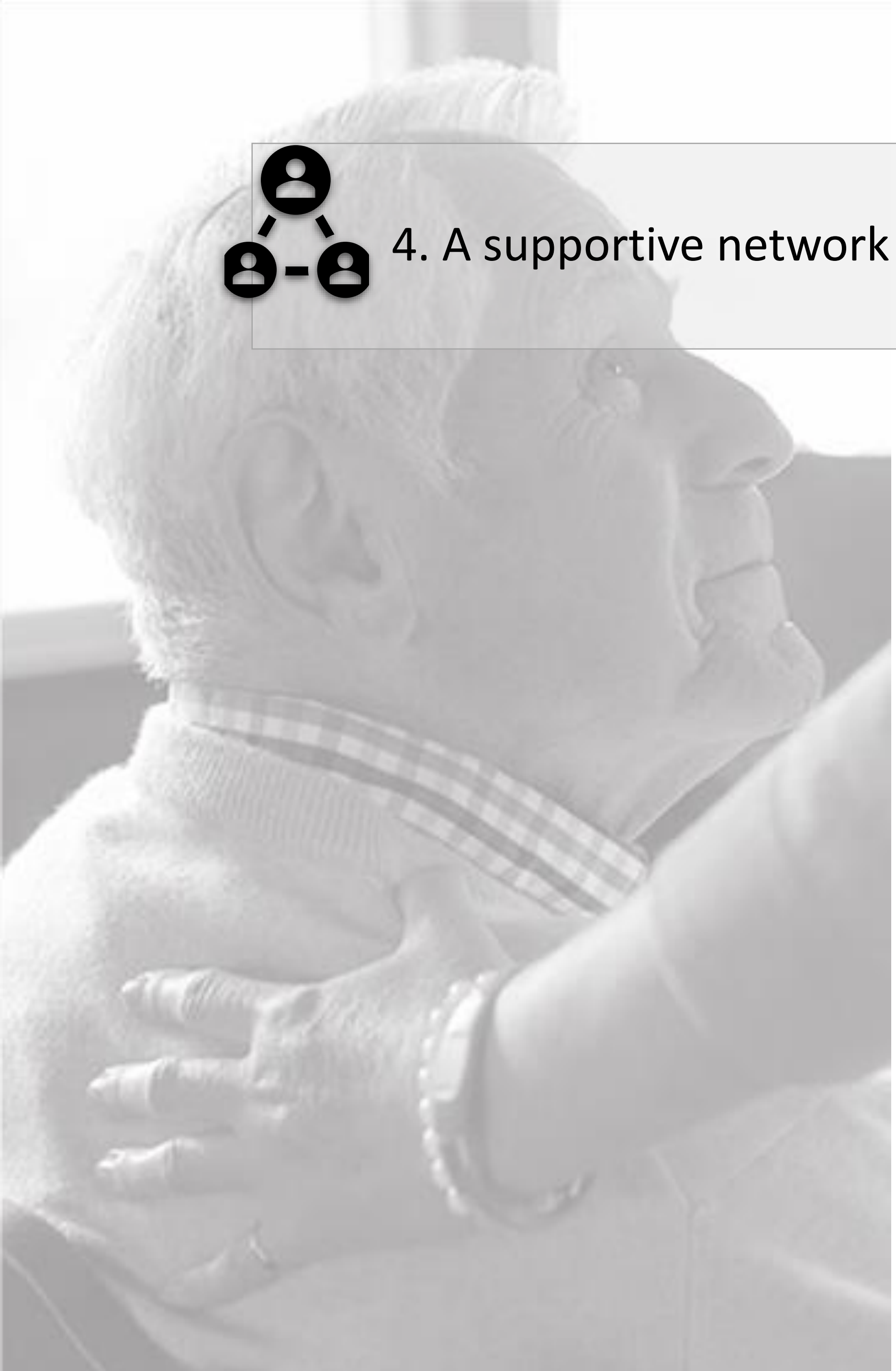
“I’m actually someone who always looks for the positive in the negative. For example, I say: ‘now I have the chance to see the sun going down’. Instead of earlier, while I used to be working or helping at home. Now this is no longer possible.”



3. Performance of essential activities supported by a team of (in)formal caregivers.

“Concerning showering. Since her fall, she [patient] never took a shower by herself anymore and has to use a chair. And if she had to go a bit deeper to wash herself I [informal caregiver] stood behind her and held her like this. Because I concluded that, that I thought, that she can tilt. It’s not possible...”

“…Not much. In the morning I have to wait until noon. Because it’s always a different time that the nurse comes to wash me. So firstly, I have to wait for that of course. Then I can put my clothes on and come downstairs.”

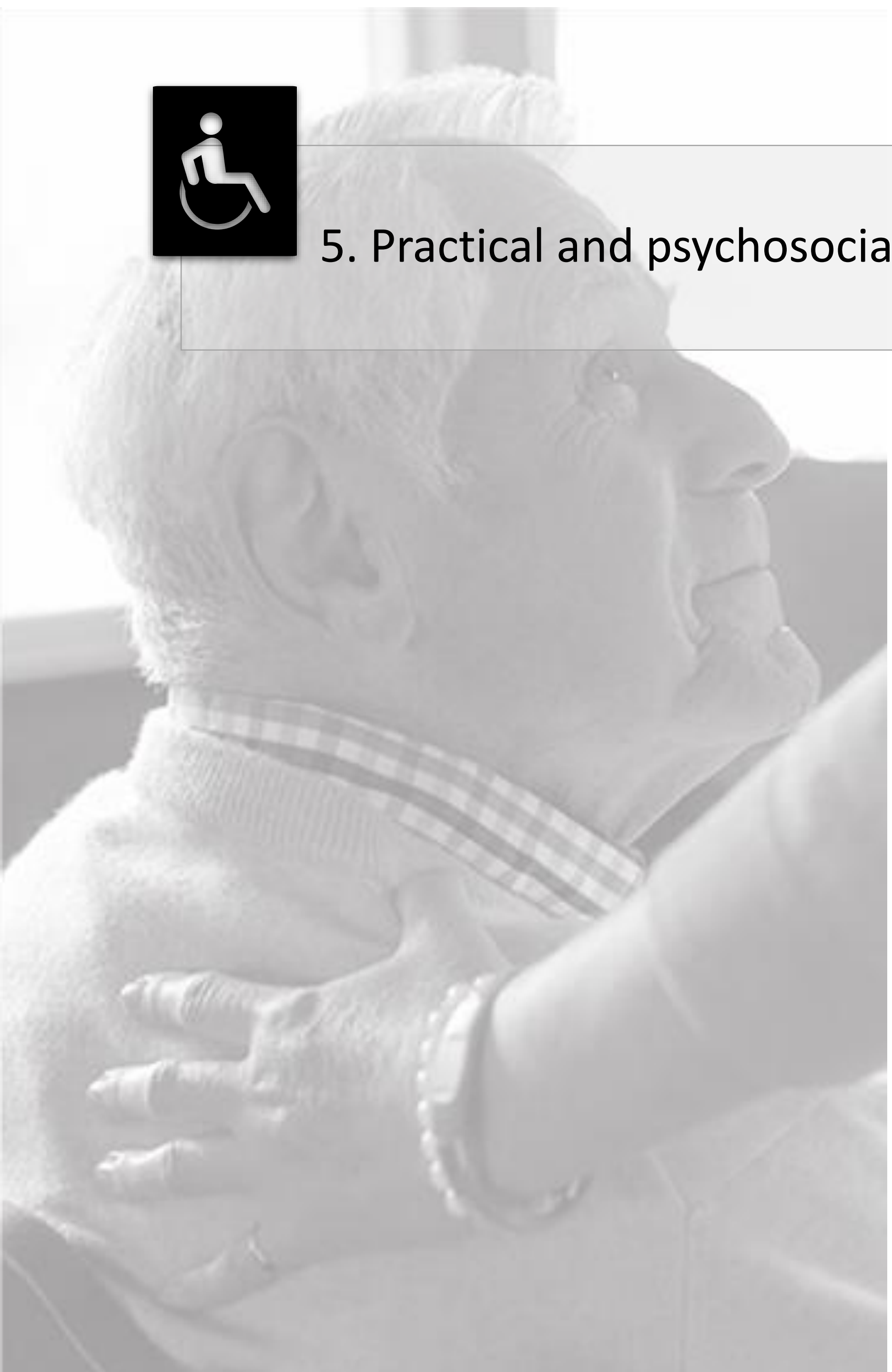


4. A supportive network to participate in society.

“They all live nearby (family). Yes, otherwise I wouldn’t be able to live here, if they would live further away. I would enjoy staying here until I die. In my small house…”

“…Because my sister has her own family, she has to take care of her household and her work, she can’t take care of me alone. That’s a bit disappointing… I’ve already discussed with my mother…when I will be alone later that I would like to have someone to support me in cooking...”

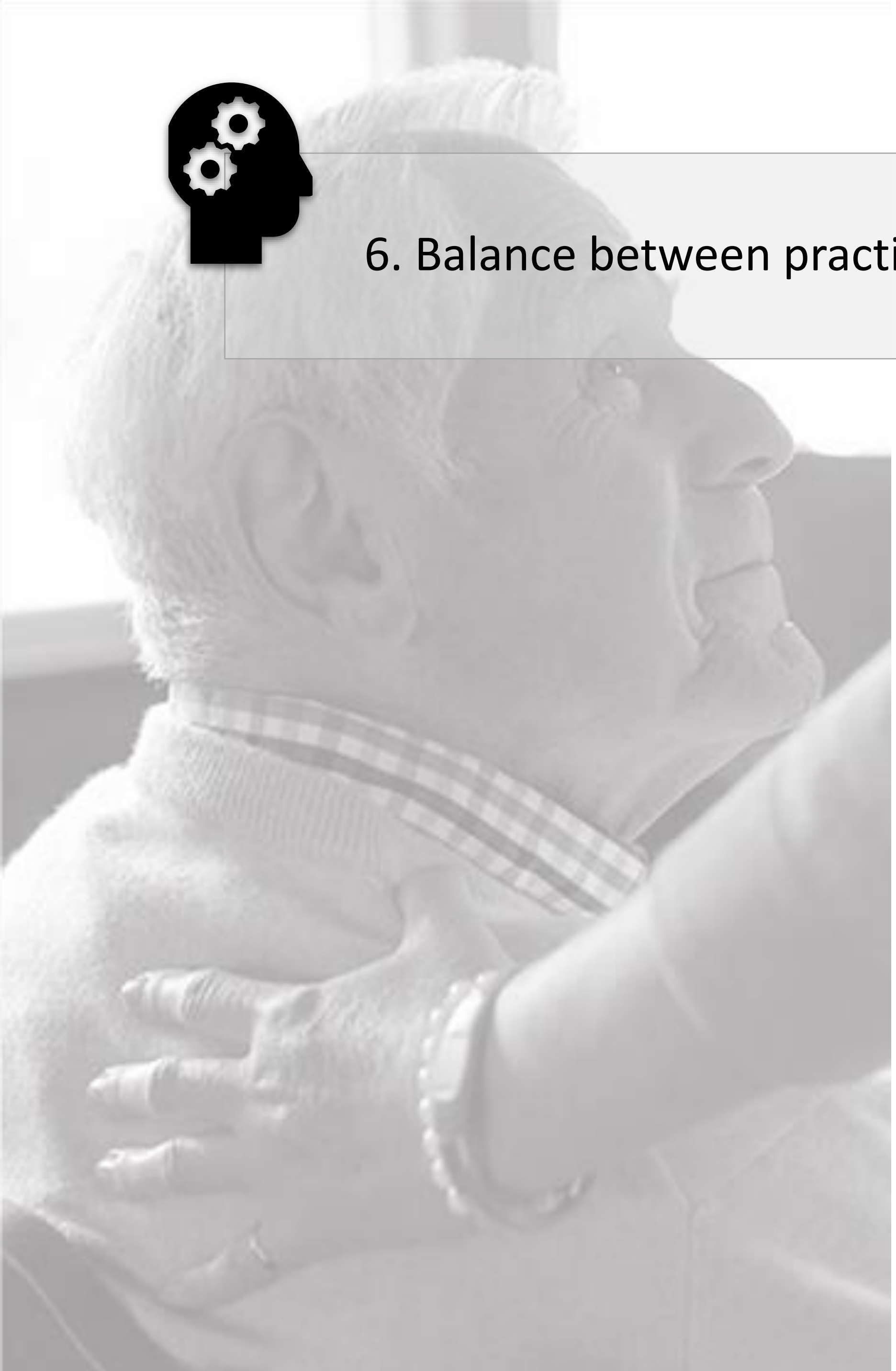
5. Practical and psychosocial support to manage meaningful and essential activities.



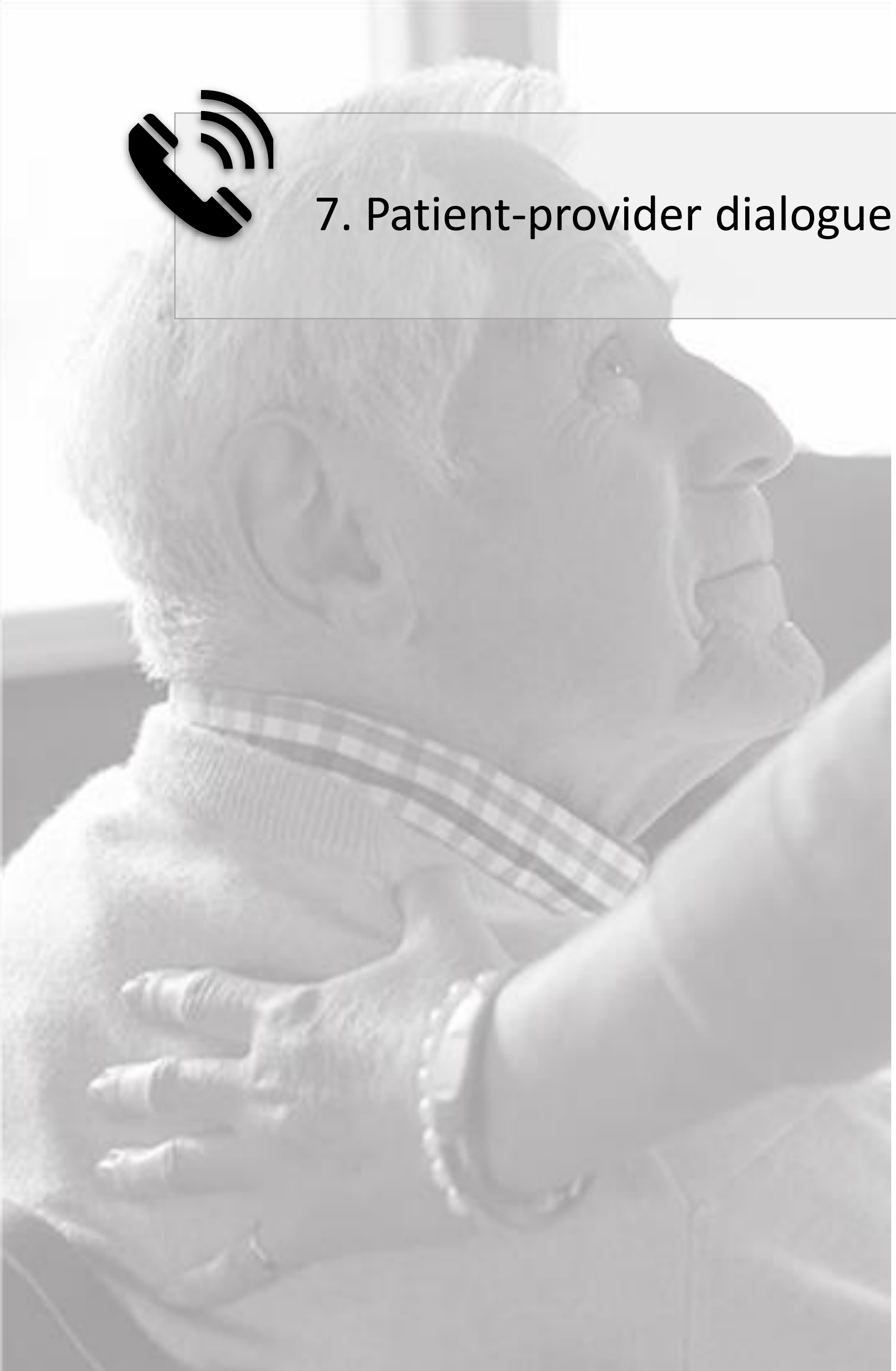
“The home owner has installed a walk-in shower so I don’t have to climb [over the bathtub which was removed] over and we have also installed a sauna [against the pain]. I think that is fantastic...I go in there once or twice a week.”

“I have a good contact with a fellow MS (Multiple Sclerosis) patient, who is worse off than me. Sometimes I invite her to come over and relax in the garden. We are both interested in culture. We exchange experiences, things we’ve been through…We don’t talk about our disease.”

6. Balance between practical and emotional caregivers’ skills.



“The most important thing is to build a relationship of trust. This isn’t possible if there is no understanding or empathy from the caregiver to the patient…Authenticity…That a caregiver also shows a piece of himself, also show that he is human. Professionalism and knowledge are also extremely important and that is where I set a high standard, the importance of education and continuing learning.”



☎ 7. Patient-provider dialogue to achieve an open communication.

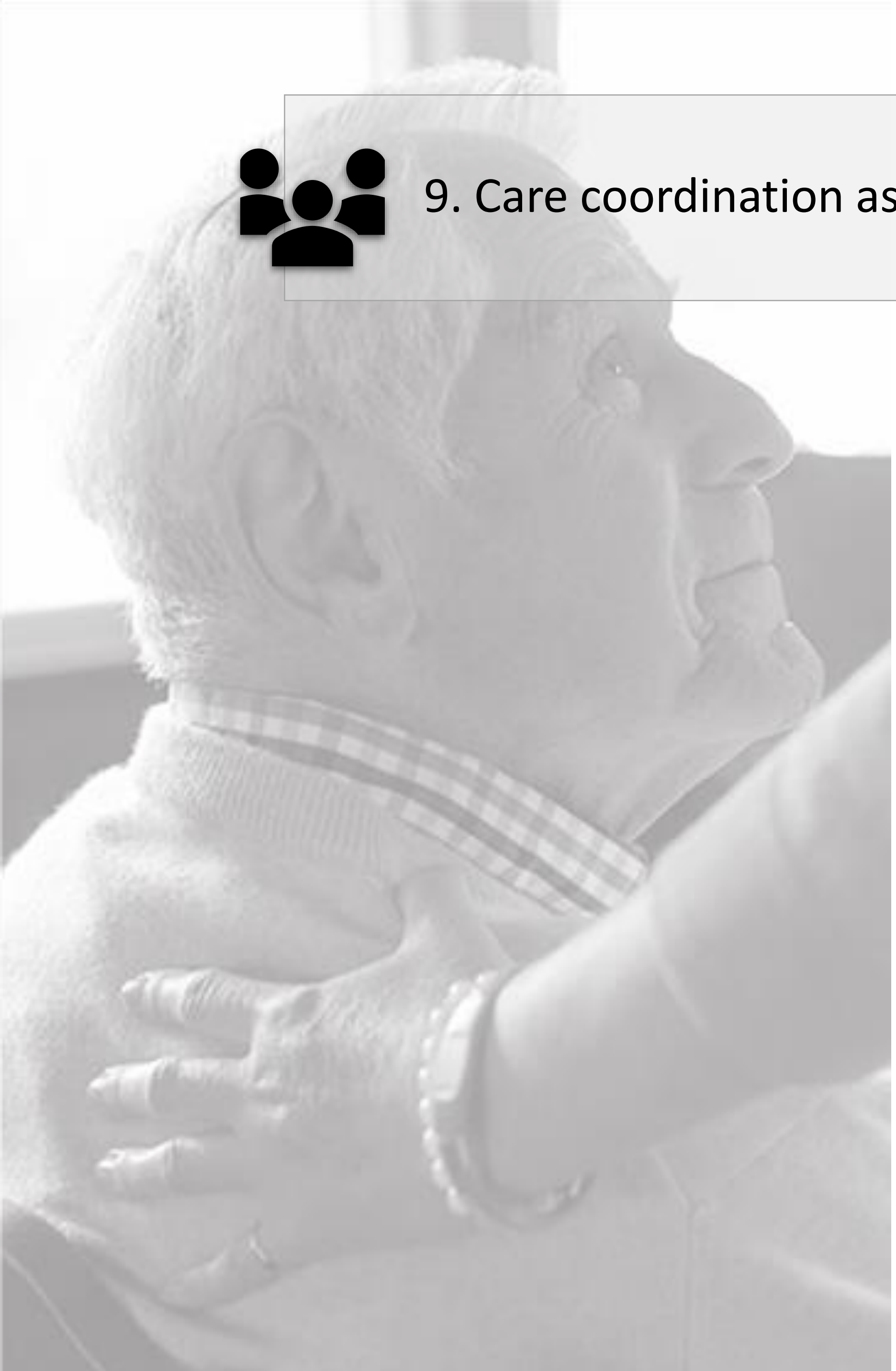
“It is not that familiar as in e.g. the rehabilitation center … You miss tenderness. In the rehab center they take time to talk about how you feel and what you want to do. I think that is important. They provide time and space to you share our problems.”

“How I was supposed to tell my husband and my children? The doctor said: ‘there is internet and a library miss.’ So, I started looking on the internet.”

8. Involvement to facilitate ‘care-decision making’.

“I am someone who enters a discussion with the medical doctor about my health,… with my family doctor and my neurologist. I want to hear the various options which I will go for.”

“If I go to the family doctor, he asks whether we should try this medication or do you prefer something else. So yes, I’m involved in the decisions.”



9. Care coordination as part of care continuity.

"Caregivers must dare to broaden their view, and look beyond their own discipline. They have to open up to have contact with other caregivers so they become one. In that case, the patient would be supported by a network of caregivers."

"And the family doctor comes on a home visit. He said to her; see you in 4 - 6 weeks…How is this possible?!? She [patient] just left the hospital, with all her worries and he said, till 4-6 weeks! …. Someone should, after leaving the hospital with a severe disease or so, warn the family doctor. Now you have to call him [FD] yourself which can takes 2-3 weeks."

10. Barriers to provide good care.

“Why should I prove that I have disabilities? It was not my first application. They [insurance company] do not realize that my condition is progressive. It was only after the renovation of our bathroom that they [insurance company] asked for a proof of invalidity…I got negative advice…Then I had to defend myself and all they asked was why I have chosen for a specific system…Now I am already waiting for nine months for an electric wheelchair…It always take so long…”

Comprehensive understanding

THE COMPREHENSIVE UNDERSTANDING

Being human	The importance of treating a patient as a person suffering from a chronic condition.
Essential activities	Not only do the patient need the environment for activities such as washing, bathing, clothing or walking. They want to achieve also other goals and purposes by doing different meaningful and essential activities.
Meaningful life	A very important thing is to find meaning in several ways: meaning in the activities they perform, meaning in their relationships with family and friends but also meaning in the relationship with their caregivers and finally meaning in life.
Balanced care	It is a constant balance between on the one hand what is strictly necessary and on the other hand what gives satisfaction and meaning in life. This goes beyond the definition of a regular care process that emphasizes the diagnosis and treatment and adds that extra level of being treated as a person.
'Reading a patient'	To support a patient, the healthcare professional need to develop different skills. A very crucial one is to read a patient's mind.
Good care	Good care means listening and giving attention to what the patients want, to what they strive for and yet to endorse them in their autonomy in an environment where they are supported by a team of professional caregivers, family and friends

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Bedankt!

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ONLINE JOINT EVENT
18, 20 en 21 mei 2021

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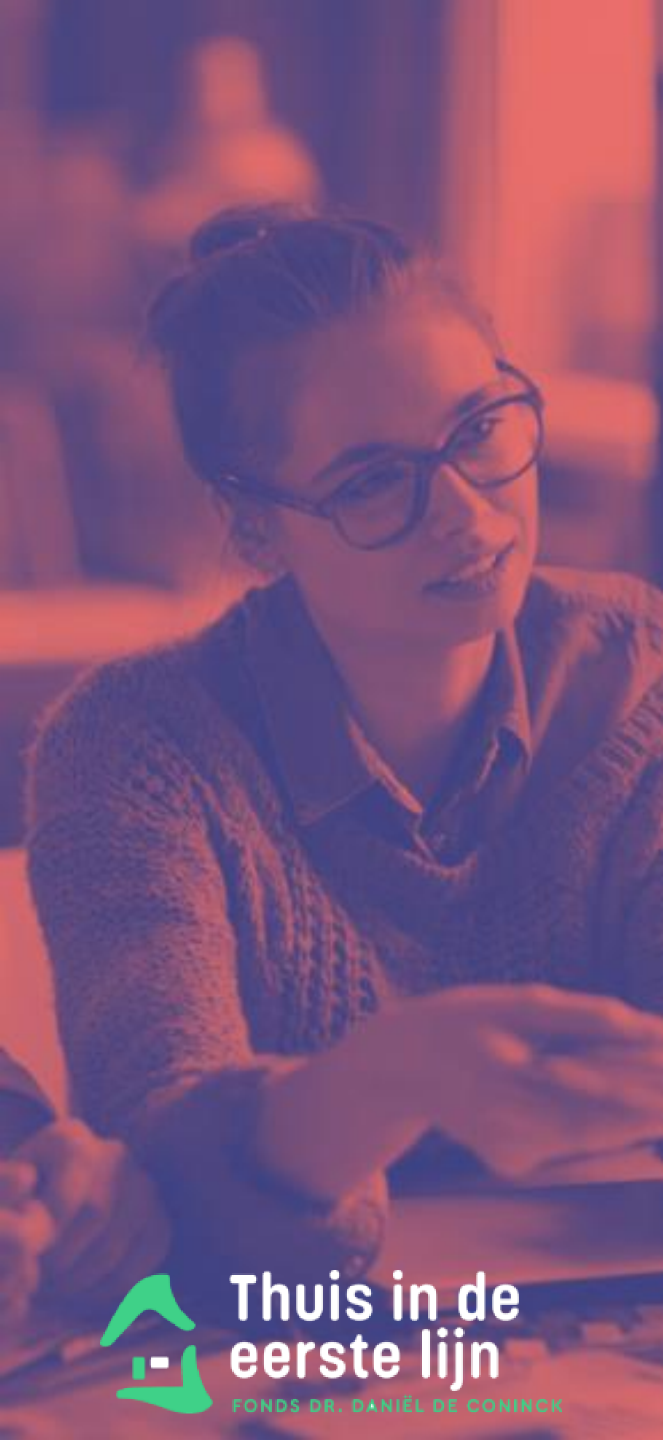

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