

Forum

Assistance in Maintaining a Positive Self-image in People with Dementia

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Abstract Dementia is a disrupting disease, most of all for those suffering from it. In essence, the disease increasingly dismantles the patient as an autonomously acting and thinking person. People with dementia continue being aware of their deterioration to varying degrees during the course of their disease. Feelings of loss of control, uncertainty, fear and grief are experienced, permanently threatening their well-being. In these difficult circumstances, maintaining a positive self-image can contribute to an optimal quality of life. Up until now little research has been done on the effectiveness of interventions that could contribute to maintaining a positive self-image. The authors will systematically discuss a number of possible interventions by means of real-life case histories. They will make recommendations for further research.

KEYWORDS: Dementia; Self-image; Quality of Life; Intervention; Rehabilitation.

Riassunto *Strategie di supporto per la conservazione di una immagine positiva di sé in persone colpite da demenza* – La demenza è una malattia devastante, in primo luogo per coloro che ne soffrono. In breve, questa malattia destruttura chi ne soffre dall'essere una persona che agisce e pensa autonomamente. Chi è colpito da demenza conserva la consapevolezza del proprio stato di compromissione lungo i diversi stadi della malattia, sperimentando sensazioni di perdita di controllo, incertezza, paura e tristezza, che mettono costantemente a rischio il benessere del paziente. In queste difficili condizioni mantenere un'immagine positiva di sé può contribuire a una più elevata qualità della vita. Fino a oggi poche indagini sono state condotte sull'efficacia degli interventi utili a mantenere un'immagine positiva di sé. Gli autori discuteranno sistematicamente alcuni possibili interventi sulla base di casi realmente trattati e offriranno suggerimenti per ulteriori ricerche.

PAROLE CHIAVE: Demenza; Immagine di sé; Qualità della vita; Intervento; Riabilitazione.



Introduction

THE SELF-IMAGE CAN BE defined as the way individuals think about themselves and

their abilities or appearance. Self-image has been conceptualized by Carl Rogers¹ as part of the self-concept, together with self-esteem and ideal self. When we ask someone to an-

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swer simple questions like “What do you think about yourself?” and “What do you believe people think about you?”, there are three possible ways of answering: (a) a self-image resulting from the way the individual sees him- or herself, (b) a self-image resulting from the way others see the individual, (c) a self-image resulting from the individual’s perception of the way others see him or her.

These three types of answers may or may not be an accurate representation of the individual concerned. All, some or none of them may be truthful and effective, depending on a series of factors influencing the way we perceive ourselves. One of the factors which could alter the representation of the self and the identity of the individual – and consequently the self-image, which may be thought of as a reflection of both these constructs – is a condition of acute, persistent, and progressive illness as is dementia.

In a systematic review Caddell and Clare² examined methods used to investigate self and identity in people with dementia. The aim of the study was to provide an outline of the current approaches to measure self or components of self in dementia, and to shed some light on the persistence of self and identity throughout the course of the disease. They reviewed thirty-nine studies, conducted with both qualitative (e.g. social constructionist model, interactionist perspectives on self, embodied selfhood, self as narrative, thematic analyses) and quantitative (e.g. identity as based on autobiographical memory, role identities, self-recognition, self-knowledge) approaches. They found considerable variations across studies, due to differences in theoretical frameworks and models of self on which the studies were based, different methods of data collection and data analysis, differences in stages and type of dementia of the participants and different sample sizes.

Nevertheless, the authors tentatively concluded that almost all of the studies provided evidence for the persistence of self at least to some extent in both the mild and moderate

to severe stages of the illness, although many studies observed some degree of deterioration in aspects of self or identity.

There are some considerations to put forward: (a) it appears that some people with dementia are able to use personal pronouns, talk about their mental and physical attributes, construct their identities in social interactions, and use and interpret non-verbal actions in order to interact with meaning and purpose;³ (b) it seems that the ability to present a coherent self-narrative is compromised, although not completely diminished, possibly due to the fading of memories as the illness progresses;⁴ (c) it appears that identity is weaker in people with dementia than in healthy older people, with a number of role identities being forgotten or reduced significantly although preserved to some extent even in those with severe dementia;⁵ (d) self-recognition deteriorates as dementia progresses;⁶ (e) there seems to be a link between the progression of the disease and a deterioration of self-recognition,⁷ furthermore, one’s sense of identity deteriorates as cognitive abilities (in particular episodic and autobiographical memory) decline;⁸ (f) the link between the different stages of severity of dementia and the persistence of self and identity remains relatively unexplored in existing research.⁹

Another concept strictly related to the self and consequently to the self-image is that of dignity. Since Kitwood’s contribution¹⁰ the notions of self, dignity and person-centred care of people with dementia have become a milestone in dementia care literature, thus stimulating a large number of both theoretical and empirical studies. Recently, Van Gennip and colleagues¹¹ proposed a conceptual model of dignity in patients with long-term serious illnesses, such as cancer, dementia, and other chronic illnesses.

Thirty-four in-depth interviews were conducted with the same number of participants in order to investigate their personal experiences with regard to their personal dignity during their illness. Following a thematic analysis, the authors developed a two-step

model of dignity in illness condition.

According to that model, illness related conditions do not affect patients' dignity directly, but indirectly, by influencing the way patients perceive themselves. Three components that shape self-perception were identified: (a) the individual self: the subjective experiences and mental qualities of the patient (i.e., sense of meaning, continuity of identity, autonomy, awareness and coping capacity), (b) the relational self: the self within reciprocal interaction with others (i.e., independency, social roles, privacy, reciprocity, feeling connected, being recognized and treated as an individual), and (c) the social self: the self as a social object in the eyes of others (i.e., understanding, respect, societal imagery).

Some of the aforementioned aspects are critical in dementia, as they can shape and strongly influence both the concept of self and the self-image of the individual. Intervention strategies (i.e., psychosocial interventions and cognitive rehabilitation) aimed at restoring or boosting the awareness and the sense of connectedness with the world, the meaning of everyday activities, the sense of autonomy and independency, the social roles and reciprocity, might have a positive impact on self-image of people with dementia, thus influencing the perception of one's own personal dignity.

Self-image and awareness in people with dementia

Are people with dementia aware of their mental deterioration? Do they consciously experience and understand what the disease is doing to them? Are they capable of reflecting upon the way they act? Can they see the implications for the people around them? Does it change the image they have of themselves?

These are important questions with no apparent univocal answers. The often heard layman's opinion that "the first stage of dementia is the worst part of the disease because then people are still realising what is

happening to them, whereas when dementia progresses, the suffering diminishes *luckily enough*" calls for making necessary nuances at the very least.¹² In people with *mild* to *moderate* dementia there is a wide variety of the level of awareness of their own deterioration. Some seem fully aware of their situation, while others seem less aware or even not aware at all.¹³ Much less is known about people with *severe* dementia.

In people with mild to moderate dementia, research also shows that in cases where there is awareness, the differences in the way they experience their disease are considerable. Some accept the deterioration and see it as an inevitable consequence of getting older, while others suffer severely.¹⁴ Moreover, it is remarkable that this variation does not only exist *between* people. Even *within* individuals we see variations.¹⁵ An example is given in case study 1.¹⁶

Case Study 1

At the Alzheimer Café Rijswijk¹⁷ on February 29th 2008, we are discussing the theme "What does dementia mean to people suffering from it?"

I am interviewing two people with dementia: Mrs De Bruin who brought both of her daughters along and my father. Two years prior I went to a memory clinic with him, because it was becoming clear that something was wrong with his brain.

Now I am talking with him about among others the decision he has made with great difficulty to stop driving cars. He knows that my brother and I have urged him to do so from the moment he was diagnosed. "I did not agree", he tells the audience. "And to be honest I still do not agree, because I drive very well. I am inviting everyone to come and join me so you can see how well I still drive. No mistakes, no one honking their horn at me, none of that!", he says belligerently. "So much is taken from you."

Mrs De Bruin offers her own opinion. "You get the impression that people think you aren't able to do anything anymore." She looks like

she's about to cry. My father nods, lips pressed together tightly. "So little is left of you," he says. After the discussion with the audience, he drinks a cup of coffee. He is very content. He has stolen the hearts of the audience, above all because he – a charming old man – spoke of his wife with genuine love and affection. He feels the appreciation and says that he has had "a wonderful evening".

"Everybody here is so kind!" Fifteen minutes later I am driving him home. He's holding a bouquet of flowers that was given to him. "For whom are these flowers?", he asks me. "They're for you", I answer. "Why have I gotten them?" "Well, I think it's quite a thing, that you allowed me to interview you in front of a room full of people and that you told them your story." "Interview?" My dad looks at me, wide-eyed. "With you?" He is shocked that he doesn't remember. "When?" "An hour ago", I say softly. "I can't remember a thing", he says shakingly. "Am I already that bad?" His good mood has disappeared at once.

*

This case study shows a mixed image even within one individual: the affected person is (sometimes) aware of the effects his disease has on him ("So little is left of you"). The consequences to his self-image seem to fluctuate: one moment he attempts to maintain his old (positive) self-image ("I still drive very well"). During and after the interview he is pleased with his performance, but when confronted with his failing memory he gets very upset and his self-image is suddenly a lot less positive ("Am I really that bad?"). In other words, the self-image of the principal person seems to be determined by the view he used to have of himself *and* a combination of thoughts and feelings on his ability to act in the present.

The image that people with dementia have of themselves is important for the way they perceive their quality of life. In a study by Dröes and colleagues¹⁸ 106 people with mild to moderate dementia were asked ques-

tions like: "What makes you happy?"; "What is important to you in your life?"; "What would you think of as annoying or unpleasant in your life?". The answers given were analyzed and categorized in the following domains: "Affect"; "Self-esteem and self-image"; "Attachment"; "Social contact"; "Enjoying activities"; "Sense of aesthetics in the everyday surroundings"; "Physical and psychological well-being"; "Financial situation"; "Safety and privacy"; "Self-determination and freedom"; "Usefulness and sense of purpose"; and "Spirituality".

Regarding the domain "Self-image", statements by the people interviewed were for example: "Staying who I am"; "Others seeing me as I am"; "Being accepted as I am"; "Being satisfied with who I am". The importance of a positive self-image regarding the quality of life of people with dementia was also emphasized by professional health care providers. They were asked which domains they thought they gave the most attention to during their daily contacts with people with dementia. The domains "Affect" and "Self-esteem and self-image" were mentioned most frequently.

The self-image of people with dementia may possibly come under great pressure. Having to experience limitations daily can have a huge impact.¹⁹ Dröes posits "preserving a positive self-image" as one of the adaptive tasks which the person with dementia has to face and describes several positive and negative "coping" mechanisms: "Denial", "Minimalizing or standardizing problems", "Emphasizing competence", "Wanting to remain involved", "Avoiding social contact", "Being dependent on others", "External attribution of problems", "Maintaining a façade", "Confabulate", and "Using humor".²⁰

Pearce and colleagues examined how twenty men with mild dementia attempted to maintain their self-image.²¹ This study showed that they attempted to find balance between maintaining their old self-image and the necessity of constructing a new one based on the new roles they have in their current

situation.

A second case study²² clarifies how that might work.

Case Study 2

Nico K. is 62 years old. He is energetic and active, professionally as well as socially. Up until December 20th 2012, that day he was sent home sick from work, when fate struck. Shortly thereafter he was diagnosed with corticobasal degeneration (CBD), a rare brain disease that leads to dementia.

His wife Marjan gives an account about the time following the diagnosis: "At a certain point everything is centred on the disease, especially in the early stages. Time is needed for everything to sink in. In the beginning Nico felt like he didn't matter anymore. He had lost his job and wasn't allowed to drive any longer. He wasn't even permitted to donate blood. It made him very gloomy".

Nico: "But after a certain period of time I picked up my life again. My life's motto has always been: "I'm here anyhow". With that I'm trying to say that, no matter the situation you're in, you can always look for things to do that could benefit others. That's what I'm doing right now. I'm keeping in touch with one of the doctors at the "VUmc" (VU University Medical Centre Amsterdam). He has sent me more than 20 papers on CBD. I'm ploughing through them, thus trying to put valid information on this disease in words that make it easier for people who have just found out they're with it to get to know what they need to know without them having to perform an extensive internet search. In accordance with my own judgements I have by now improved and complemented on a couple of translations of material on CBD from Canadian and American websites. It's very important that people don't have to go on random searches and stumble upon awful stories or end up not seeing the forest for the trees". Marjan: "That's Nico's attitude. Always!"

His daughter Suzanne: "I find that admirable, especially given the situation my dad is

in now: at a young age losing his job and not being able to do certain things any longer. That he is trying to give a positive twist to things is impressive". Nico: "That's not admirable at all, that's just in accordance with my view on life".

Dealing with the consequences of dementia: Psychosocial interventions

In a comprehensive review, Dröes and colleagues²³ give an outline of effective psychosocial interventions (a.o. psychomotor therapy, behaviour therapy, reality orientation, music therapy, reminiscing, validation, integrated dementia care, sensory therapy, simulated presence therapy, pet therapy) to help people with dementia with dealing with the consequences of their disease. Several interventions have favourable effects on "maintaining an emotional equilibrium", as is evidenced by a decrease in neuropsychiatric symptoms as aggression, apathy, unrest, depression and fear. Positive results have also been reported regarding "dealing with one's limitations".

However, research regarding helping in maintaining a positive self-image is scarce. Only a couple of studies claim a positive effect with interventions like simulated presence therapy²⁴ and emotion oriented care.²⁵ When having a closer look at these studies, one could pose the question to what extent the reported positive effects ("less agitation and withdrawn behaviour", and "happy facial expressions";²⁶ and "less dissatisfaction with one's own situation")²⁷ are rather related to general feelings of well-being than to maintaining a positive self-image specifically. A recent review study by Testad and colleagues²⁸ into the effects of personalized psychosocial interventions does not show any positive effects on maintaining a positive self-image either.

In spite of this lack of scientific studies, lots of practice experience is acquired on interventions aiming at boosting a positive self-image in people with dementia. At Dutch "meeting centres" for instance, where "integrated dementia care" is offered to people

with dementia and their informal caregivers, purposeful and successful efforts are aimed at assistance in dealing with the consequences of the disease.²⁹

In the next 4 case studies a picture is drawn of the approach at hand.

■ Case Study 3

Client: Mrs A., 68 years old.

Diagnosis: Alzheimer's disease. Stage: mild dementia.

Previous history: Comes from a large family. She has 6 sisters and a brother. She has undergone postnatal brain surgery. Because of that she's suffered from mild cases of memory loss. As a result she couldn't keep up that well with her brother and sisters. During her youth her father belittled her because of her disability. Her father was an able gymnast. Every family member was a gymnast, but A. was the odd one out because she didn't perform that well.

She was married but her husband left her, taking all of their savings with him. In 1989 she was involved in a traffic accident. After that she had difficulties reading. Ever since the accident she walks with the assistance of a wheeled walker. She loses her balance easily and is in a lot of pain. She lives on her own. She has some friends that don't live close by but call her on the phone regularly. She has one good lady friend who visits her regularly.

The analyses of the guiding question and the primary aim of the psychosocial assistance: At the start of her participation in the "meeting centre" she indicated feeling lonely. She noticed becoming more passive whereas she had a lot of hobbies in the past like making 3D cards, dancing and listening to music. Her self-image seems to be a negative one. She feels like she is inferior to the people around her. Therefore the aims of the psychosocial assistance are: stimulating social contacts, reactivating and boosting a positive self-image.

Assistance strategies: Involving Mrs A. in

the social and recreational activities at the centre. Emphasising activities she prefers as well as activities she's good at. The dance related activities at the centre serve as a starting point. Complimenting her on her accomplishments and her contributions. Getting her to keep a diary and letting her talk about her experiences.

Implementation of the action plan: *The initiatives Mrs A. shows will get encouraged. Reading her diary with her consent every time she visits and sharing it with other visitors. When she is dancing her preferences in music will be taken into account and Mrs A. will be encouraged to show dances to the other participants.*

Results: *Mrs A. participates in a lot of activities enthusiastically. She also gets complimented by other clients. She dances while standing in one place without the aid of her wheeled walker and is able to move around the room with the aid of her wheeled walker. She enjoys dancing very much. When she's applauded she is radiant. She talks about her previous experiences with dancing and she demonstrates the salsa.*

When she's dancing without the aid of her wheeled walker the attending staff supports her. She likes being touched. Talking about her diary makes her feel like she matters. Her friends indicate that nowadays she initiates phone calls and that when she does so, she begins talking about the role she plays in the dance activities at the meeting centre right away.

Evaluation: *She feels acknowledged, taken seriously and appreciated for who she is. This gives her confidence and it makes her experience fun in her life. Towards friends she's more positive about herself.*

■ Case Study 4

Client: Mrs B., 78 years old.

Diagnosis: Alzheimer's disease. Stage: Mild dementia.

Previous history: *Mrs B. had 3 brothers with whom she spent a lot of time. She played checkers with them fanatically. She has always been an independent person. She has been a single mother from when her daughter reached the age of 3. She ran a chocolate shop up until she turned 76 years old. She had a heart attack 20 years ago. She gets tired easily the last couple of years. She suffers from memory loss and can't handle money any longer.*

The analyses of the guiding question and the primary aim of the psychosocial assistance: *Mrs B. is lonely, according to her daughter. Her forgetfulness has caused her to become insecure. She has a fear of doing things the wrong way, of making mistakes. She thinks of herself as "lame". The primary aims of the psychosocial assistance are bringing her into contact with other people and boosting a positive self-image.*

Assistance strategies: *Preventing Mrs B. from having feelings of failure and letting her experience as much as possible that there are things she can do very well. Talking to her about her achievements as a single mother and entrepreneur.*

Implementation of the action plan: *Her daughter selects photos with her that say something about the important moments in her life. Under the supervision of one of the meeting centre's professionals she tells a small group of trusted people more about the photos. She participates in a small checkers tournament every week with 3 male clients of the meeting centre.*

Results: *Mrs B. enjoys talking about the good things in her life. She plays checkers with her male opponents enthusiastically and wins every time. She also used to beat her brothers at playing checkers and she talks about that a lot. Her opponents compliment her a lot. After a difficult start Mrs B. says she enjoys going to the meeting centre.*

She becomes more and more active. On her own initiative she clears the table and helps

doing the dishes. She also gives language lessons to a South American volunteer. Her daughter also endorses her mother feeling safe and at home at the meeting centre.

Evaluation: *Mrs B. is more positive about herself. Reviving pleasant memories gives her confidence. Her daughter says that her mother has regained her old vigour.*

■ Case Study 5

Client: *Mr C., 83 years old*

Diagnosis: *Alzheimer's disease. Stage: mild dementia.*

Previous history: *Mr C. comes from a family of 14 children. He would have liked to go to college, but that wasn't possible because of financial reasons. He has a brother who is a teacher. He would have liked to become one as well. He finished technical school and he has been a lathe operator. He got divorced when he was 40 years old. He lives on his own. He has a daughter and a son.*

His daughter visits him regularly and cooks for him on those occasions. He sees his son at a more irregular basis. Mr C. has always had a bit of a gloomy disposition. He used to like playing chess and bridge. He used to be a member of a bridge club, but he doesn't go there anymore.

The analyses of the guiding question and the primary aim of the psychosocial assistance: *According to his daughter Mr C. is gloomy and lonely. He feels like he's not worth much any longer and he doesn't really meet any people anymore. Because of his gloominess his family doctor has referred him to a psychiatrist. The primary aims of the psychosocial assistance are gaining social contacts and boosting a positive self-image.*

Assistance strategies: *Encourage social contacts with other clients and counsellors at the meeting centre. Giving him positive experiences with things he is good at.*

Implementation of the action plan: *Letting Mr C. play chess with other clients. Stimulating him doing things that require him working together with others or doing things that are helpful to others. Complimenting him on his contributions and his accomplishments.*

Results: *At the start of his participating in the meeting centre he kept himself apart from the others. After entering the room he'd find himself a place at a table alone. He found it difficult hearing the words "Alzheimer's disease" and he denied suffering from the disease. In the beginning he attended twice a week but left directly after lunch. During group conversations he got annoyed by people reading or talking about their studies.*

Efforts to activate him gradually became successful. He played chess with other clients with great concentration. He increased his contacts with other clients. He started helping other clients. He took care of the vegetable garden, he assisted the "walk club" when there were not enough volunteers present, he supported the staff in psychomotor therapy and he gave Dutch lessons to a Tibetan trainee. He found all of this thoroughly rewarding and he volunteered to call him whenever we should be in need of assistance.

Evaluation: *Especially feeling useful gave him a boost. His daughter indicates that he's in a better mood. Nowadays he even shows up on days when he isn't really expected to.*

■ Case Study 6

Client: *Mrs D., 75 years old.*

Diagnosis: *Alzheimer's disease. Stage: mild dementia.*

Previous history: *Mrs D. grew up in an orphanage after her father passed away. Her mother got remarried, but didn't allow Mrs D. to become a part of the new family. Mrs D. got divorced at a young age and raised her 2 children on her own. To make a living she cleaned houses. She has always been very nervous. She*

has always done everything for her children and hardly anything for herself. She has barely known a social life. She has always lived a frugal life. She has good relationships with her son and daughter. She talks about herself in a negative way.

The analyses of the guiding question and the primary aim of the psychosocial assistance: *Mrs D. doesn't have a social life and is very lonely according to her children. Because of her forgetfulness and her awareness that she's with Alzheimer's disease, she's even more nervous than before. She's sad and has a negative self-image. The primary aims of the psychosocial assistance are gaining social contacts and boosting a positive self-image.*

Assistance strategies: *Encouraging social contacts with others. Giving her positive experiences with things she is good at.*

Implementation of the action plan: *After her first visit her son indicated that the other clients gave his mother a fright. After the second visit it became clear she found it very difficult being confronted with what the disease is capable of doing to people. We nevertheless decided on starting with her visiting one day a week on a day when some younger people were present as well. She had a click with a younger woman. Under guidance of a professional they talked about Alzheimer's disease. Although she had never participated in creative activities before, the decision was made to get her involved in creative activities nonetheless. This in search of activities that would give her pleasure and appreciation by others.*

Results: *The talks did her good. She developed a friendship with her conversation partner. Regarding creative activities she managed making beautiful collages out of paper ribbons. She enjoyed this noticeably and she was surprised by the results. During the meeting when the results of the creative activities were shown, she stood up and told about her work. At that moment her children hardly recognized their*

mother because of the confidence and pride she showed.

Evaluation: *The friendship with her conversation partner gives her confidence. Her creative collages and the feedback she gets from others give her a feeling of pride. She is more positive about herself.*

The casuistry shows a similarity in approach and results:

- (1) An assistance strategy is determined and an action plan is formulated and executed after analysis of the guiding question and the primary goal of the assistance;
- (2) The life history of the client is taken into account, especially aspects thereof that were important to the self-image in the past (before the disease);
- (3) The emphasis is on things the client can still do and likes doing;
- (4) The interventions give meaning: the client is being enabled to achieve things that not only have meaning to himself but are of value to others as well;
- (5) Activities concerning the reminiscence of positive life events, the helping of others and creative means of expression are successful;
- (6) The appreciation by the client of the way he or she acts and especially the appreciation of relevant others play a decisive role.

■ Cognitive rehabilitation

Another interesting possibility of helping people with mild to moderate dementia maintaining a positive self-image is to be found in the field of cognitive rehabilitation. This is defined as “intervention strategies or techniques that enable patients and the peo-

ple around them to live with, sidestep or diminish the limitations resulting from brain damage.³⁰

Errorless learning³¹ appears to be a promising method. Loss of memory, executive functions and learning abilities are *processes* that increase in seriousness gradually.³² During the course of the disease the patient might still be able to (re) learn things, albeit that the possibilities for learning will diminish more and more as the dementia progresses.³³ A combined use of learning programmes and supporting technology³⁴ also offers opportunities.

In a study by Perilli and colleagues,³⁵ people with mild to moderate dementia (re) learned a domestic activity: making coffee. A procedure involving visual instructions (video) was compared to verbal instructions. The activity that had to be learned was divided up into 18 steps. All participants learned to make coffee. Both interventions proved to be equally effective. The average percentage of correct responses before the interventions (baseline) varied between 20 and 40. The average percentage of correct responses during the interventions was above 90. Caffò and colleagues³⁶ taught people with moderate to severe dementia to find their way in the nursing home they were living in: a route from their bedroom to the living room and a route from the day treatment area to the coffee corner. Two methods were compared: a backward chaining procedure and a procedure with supporting technology. All participants learned their way around. Importantly, participants in both studies enjoyed participating and found satisfaction in their achievements.

Recently De Werd and colleagues³⁷ wrote a practical manual for health care professionals on errorless learning by people with dementia. The (re) learning of skills can enable patients to perform those activities independently for an extended period of time. This can have a positive effect on the general activity level of patients as well as on their self-esteem and motivation to do things).³⁸

Another promising approach is currently

being realised in the “*Dementalent*” project.³⁹ In this project, starting point are the possibilities and the talents of people with dementia and the meaningful utilization thereof. This is done by enlisting them as volunteers at clubs, community centres, landscape maintenance, schools and churches. The first project has been running for more than a year now and is initiated by Care Group Apeldoorn and the Dutch Forestry Commission. There are currently 14 people with dementia working as volunteer at Radio Kootwijk. The volunteers are working in the woods. They perform maintenance of buildings and they help in building up and clearing the infrastructure for special events.

This has proven to be contributing to a meaningful way of spending the day. They feel like usefully contributing to society once again. They indicate that working together, helping each other, and sharing experiences regarding living with dementia are also very important. “I’ve gotten a taste of the real world again since starting working as a volunteer. I’m no longer experiencing fear of failure and I feel like being involved in society”, one of the participants says. An informal caregiver says: “Once again my husband comes home like he used to come home from work: satisfied!”

■ Possibilities for people with severe dementia

There have even been fewer studies done on interventions to help people with severe dementia maintaining a positive self-image, than studies regarding people with mild to moderate dementia.

Van Bommel⁴⁰ describes his life with his partner Thom who got to suffer from frontotemporal dementia. In only a couple of years Thom transforms from a sparkling, clever and social partner into an insecure and short-tempered man with severe dementia. However, there are still points to start from in assisting him, like the following case study illustrates.

■ Case Study 7

“Look, there it is: Thom, Thom Houweling. ‘It’s me!’, Thom says while pointing at his name on a painting hanging in our hallway. He keeps on painting enthusiastically: every week at least 3 new pieces of art are created. At our home, in our long and high hallway there are 50 genuine ‘Houwelingen’ hanging on the wall in 5 rows above each other at this moment. And there are even more. Nobody entering our home can pass them without noticing them which is exactly the purpose. Thom beams every time people look at his paintings and admire them.

He explains his art in his own way. In between he’ll look at me expectantly hoping that I’ll add some nice remarks, that way making sure the attention will be on his paintings even longer. In order to keep painting meaningful to Thom I’m continuously looking for possible ways of doing things with the fruits of all his labour. For that reason I often ask him –when we are visiting people– to make them a special painting as a present. He doesn’t do that just like that however. He usually says: “Maybe, I’ll think about it”. And then he starts promptly anyhow. Currently Thom is painting our Christmas cards.

On postcard sized watercolour paper he paints colourful and elegant little pictures. He has finished 50 of them. We need more than a hundred. Every day he spends up to 3 quarters of an hour painting without interruption, which is the limit of keeping his attention on something. All in all painting has proven to be a meaningful and rewarding activity for Thom that helps him maintain a positive self-image.

Furthermore there are indications that listening to music can contribute to calling up positive personal memories. Hoogeveen and colleagues⁴¹ have developed an online radio station for people with dementia: Radio Remember. This project aimed at people with severe dementia reviving positive memories and feelings with the aid of music. For that reason the radio station plays only “relevant” music – music that ties to the experiences of the target audience. The focus therefor is on

music from the time between 1944 and 1963. This has led to a selection of more than 3100 songs. The radio station was tested in more than 20 communal living rooms of nursing homes of people with severe dementia.

Qualitative (interviews with people with dementia, and their informal and professional caregivers) as well as quantitative data (observations of behaviour before during and after listening to the music) were collected over a period of 3 months. 56% of the nursing home residents talked about listening to the music in a positive way. They found the music “beautiful” or “nice to listen to”. 38% of the residents indicated getting positive thoughts because of the music.

They thought of “cosiness”, “being happy”, or “days in school” and they remembered positive events from their live history (“Uncle Stef used to play the piano beautifully at home!”). Of the caregivers interviewed 90% was positive about Radio Remember. A characteristic remark is: “I’m very happy with the music. I see people reacting to it in a positive way, each in his or her own fashion”. 77% notices positive responses to the music by residents (a.o. singing, humming, moving along and being happy). 68% sees more interaction with residents and between residents when the radio is on.

Residents and staff sing together, residents talk about the old days and about music and residents laugh more than they usually do. Behaviour observations showed clear positive results in one third of the residents (clapping their hands, moving rhythmically, anxious mood disappearing, dancing with neighbour, singing along, looking for eye contact, laughing, gloomy mood improving and looking for contact).

An example of how listening to music can make someone remember who he was, thus restoring a positive self-image temporarily, is given in the following case study.

■ Case Study 8

Henry is suffering from dementia and has

been living in a nursing home for the last ten years. He is withdrawn and only answers closed questions. But that changes when he is listening to his favourite music from the 50’s with an iPod and headphones. He enjoys himself and he moves and sings along. When someone tries to strike up a conversation about music after a couple of minutes, he proves to be able reminiscing old memories.⁴² He names his favourite artists, talks about dancing parties and sings a song spontaneously.

Henry remembers who he used to be. That this effect is only a temporary one seems of less importance. Repeating the intervention leads to the same result every time.

■ Summary, discussion and conclusions

Many people with mild to moderate dementia are aware of their limitations.⁴³ With that there are differences between *and* within people in the way they experience those limitations.⁴⁴ Much less is known about this regarding people with severe dementia.

The self-image of people with dementia is important to the way they perceive the quality of their life.⁴⁵ In the course of the disease the self-image of people with mild to moderate dementia can become under severe pressure.⁴⁶ Therefore maintaining a positive self-image is one of the adaptive tasks people with dementia are faced with.⁴⁷

Impact studies on psychosocial interventions aimed at maintaining a positive self-image are scarce.⁴⁸ Effects that were found were sooner related to a general feeling of well-being than to maintaining a positive self-image in peculiar.⁴⁹ The casuistry that was presented clearly shows some favourable practical experiences.

Cognitive rehabilitation whether with the aid of supporting technology or not,⁵⁰ offers opportunities to boost maintaining a positive self-image in people with mild, moderate and severe dementia especially in the form of errorless learning. Regarding people with severe dementia, music therapy seems to offer very promising possibilities.

One of the limitations of the scarce research on interventions to boost the self-image of people with dementia may be attributed to the construct “self-image”. This is an abstraction and therefore it is not directly observable. However it could likely be operationalized. Perhaps we are lacking in a good definition that could lead to operationalization, which is a demanding problem.

A possible attempt at defining could be: “the whole of thoughts and feelings that people have about themselves and their reflection thereon in relation with their observations and their assessment of the way they act in the current situation”. A definition like that, that seems valid regarding people without cognitive limitations, may not take the (dis)abilities of people with dementia into account enough and is furthermore difficult to put into operation.

A simple definition, for instance: “All that someone says about the way he or she acts”, poses its own problems because it does not take into account the emotional reactions that are so characteristic to the perceptions of people with dementia. Furthermore the self-image of people with dementia may not be a condition that is permanently manifest. Perhaps as dementia progresses thoughts and feelings regarding self-image become more and more short-lived and varying, and more dependent on events that happened immediately before.

With this, choices have to be made and the operationalization of the construct has to get defined precisely and concretely. Next, impact studies on psychosocial interventions in order to maintain a positive self-image are of the utmost importance. The interventions will have to get geared to the characteristics of the self-image from before the disease manifested itself, the seriousness of the disease, the type of dementia (for instance: lack of self-insight is mentioned as one of the characteristic symptom signs in people with frontotemporal dementia);⁵¹ characteristics of the person and his or her life story and his or her social and surrounding factors.

Notes

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⁶ See F. BIRINGER, J.R. ANDERSON, *Self-recognition in Alzheimer's Disease: A Mirror and Video Study*,

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⁷ See F. BIRINGER, J.R. ANDERSON, *Self-recognition in Alzheimer's Disease: A Mirror and Video Study*, cit.; S. FAZIO, D.B. MITCHELL, *Persistence of Self in Individuals with Alzheimer's Disease*, cit.; R.P. GREWAL, *Self-recognition in Dementia of the Alzheimer Type*, cit.

⁸ See J. COHEN-MANSFIELD, H. GOLANDER, G. ARNHEIM, *Self-identity in Older Persons Suffering from Dementia: Preliminary Results*, in: «Social Science and Medicine», vol. LI, n. 1, 2000, pp. 381-394; M.A. MILLS, *Narrative Identity and Dementia*, cit.; See D.R. ADDIS, L.J. TIPPETT, *Memory of Myself: Autobiographical Memory and Identity in Alzheimer's Disease*, cit.; Naylor & Clare, 2008.

⁹ L.S. CADDELL, L. CLARE, *The Impact of Dementia on Self and Identity*, cit.

¹⁰ See T. KITWOOD, *Dementia Reconsidered: The Person Comes First*, Oxford University Press, Buckingham 1997.

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¹³ See L. CLARE, *Managing Threats to Self: Awareness in Early Stage Alzheimer's Disease*, in: «Social Science and Medicine», vol. LVII, n. 6, 2003, pp. 1017-1029; A. PHINNEY, *Fluctuating Awareness and the Breakdown of the Illness Narrative in Dementia*, in: «Dementia», vol. I, n. 3, 2002, pp. 329-344.

¹⁴ See L. CLARE, *We'll Fight it as Long as we Can: Coping with the Onset of Alzheimer's Disease*, in: «Aging & Mental Health», vol. VI, n. 2, 2002, pp. 139-148; M. DE BOER, C. HERTOOGH, R. DRÖES, I. RIPHAGEN, C. JONKER, J. EEFSTING, *With Dementia: The Patient's Perspective. An Overview of the Literature*, in: «International Psychogeriatrics», vol. XIX, n. 6, 2007, pp. 1021-1039; E. STEEMAN, J. GODDERIS, M. GRYPDONCK, N. DE BAL, B. DIERCKX DE CASTELE, *Living with Dementia from the Perspective of Older People: Is it a Positive Story?*, in: «Ageing and Mental Health», vol. XI, n. 2, 2007, pp. 119-130.

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²⁵ See E. FINNEMA, R.M. DRÖES, T. ETTEMA, M. OOMS, H. ADÈR, M. RIBBE, W. VAN TILBURG, *The Effect of Integrated Emotion-oriented Care versus Usual Care on Elderly Persons with Dementia in the Nursing Home and on Nursing Assistants: A Randomized Clinical Trial*, in: «International Journal of Geriatric Psychiatry», vol. XX, n. 4, 2005, pp. 330-343.

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³³ See L. CLARE, *Working with Memory Problems*, in: E. MONIZ-COOK, J. MANTHORPE (eds.), *Early Psychological Interventions in Dementia*, Kingsley, London 2009, pp. 73-80; L. CLARE, B. WILSON, G. CARTER, K. BREEN, A. GOSES, J. HODGES, *Intervening with Everyday Memory Problems in Dementia of Alzheimer Type: An Errorless Learning Approach*, in: «Journal of Clinical and Experimental Neuropsychology», vol. XXII, n. 1, pp. 2000, pp. 132-146.

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⁴⁰ See S. VAN BOMMEL, *Ik ben niet kwijt*, Prometheus, Amsterdam 2012.

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⁴² See www.youtube.com and search terms "Henry", "music", "dementia".

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⁴⁴ See L. CLARE, *We'll Fight it as Long as we Can: Coping with the Onset of Alzheimer's Disease*, cit.; M. DE BOER, C. HERTOOGH, R. DRÖES, I. RIPHAGEN, C. JONKER, J. EEFSTING, *With Dementia*, cit.; F.R. HOOGEVEEN, „Dat onthouden kan ik wel vergeten". In gesprek met mijn dementerende vader, in: «Denkbeeld», cit.

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