The Use of 'Talking Mats' by Persons with Alzheimer in the Netherlands: Increasing Shared Decision-Making by Using a Low-Tech Communication Aid

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Abstract

Background: Alzheimer's disease (AD) is the most frequent form of dementia. Frequently decisions are made for the persons with AD because of problems with communication. To avoid this, the low-tech communication aid Talking Mats (TM) can be used.
Aim: The study was threefold: 1) to observe the effect of TM on shared decisions in communication with people with AD; 2) to assess if TM affects the use of language by people with AD in conversation; 3) to get insight in the usability of the Dutch version of TM for persons with AD and their relatives.
Methods: The study followed a cross-over design. There for TM was translated into Dutch for use. TM was used in communication between persons with AD and a relative (n=6). Shared decisions were evaluated by using the observation list OPTION which was filled in by an external observer. The language used by the participants with AD was analyzed as regards seven language elements which are typical for Alzheimer. Semi-structured interviews took place.
Results: Shared decisions significantly increased. There was no effect of TM on the frequency of the seven analyzed language aspects.
Conclusion: The Dutch version of TM is an efficient communication framework which supports the process of shared decisions between persons with AD and their relatives.

Keywords: Alzheimer's disease, Augmentative and Alternative Communication (AAC), dementia, shared decisions, Talking Mats

The language and communication changes associated with Alzheimer's Disease (AD) are one of the first symptoms that are noticed by relatives (Byrne & Orange, 2005). Dementia gradually affects the way the person communicates. Their ability to present rational ideas and to reason diminishes. In general these problems are experienced as very stressful (Byrne & Orange, 2005).

Individuals with dementia typically experience problems with memory, language, and other abilities. These problems impair social functioning: conversations with others can be difficult and awareness of declining abilities can be distressing. It is common for individuals with communication problems such as dementia to withdraw from social activity (Dalemans et.al., 2010).

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Discovering ways to maintain the involvement of persons with AD in social activities and making decisions about daily living is important to preserve their identities (MacRae, 2011; Bridges & Wilkinson, 2011). The involvement of these persons in making decisions contributes to the quality of life because he or she then has the possibility to clarify wishes and preferences (Menne & Whitlatch, 2009; Murphy et.al., 2010). Successful transitions may be assisted by ensuring that the person with dementia has input into decision making (Sury et.al., 2013).

Since over sixty percent of the caregivers experience mental stress and eighteen percent experience severe mental stress in addition to misunderstanding and frustrations in communication, the use of a communication aid could also be helpful for the relatives and the caregivers (Francke, Peeters, Spreeuwenberg, Van Beek, & Zwaanswijk, 2009).
It can also be used to accomplish shared decisions. "Shared decision-making is an interactive process in which both parties (person and carer) are equally and actively involved and share information in order to reach an agreement, for which they are jointly responsible" (Härter, 2010).

Talking Mats is such a communication framework of which the positive effects on shared decision-making have been demonstrated for the English version for different groups of people with a communication disorder (Cox et.al., 2010;Murphy et.al., 2011).
Talking Mats consists of a mat and a set of pictograms. A manual and a DVD with videos of the use of Talking Mats by different target groups support the correct use of Talking Mats. Talking Mats is used during a conversation. The topic, for example daily activities, is fixed before the beginning of the conversation. A pictogram for this topic is placed on the mat as a reminder. The person without a communication disorder leads through the conversation by asking open questions such as "what do you think about reading?". By each question, a pictogram which illustrates the asked aspect is shown or given to the person with the communication disorder. This person has to state whether he thinks positive or negative about this aspect. There is also the option to state that he is not sure about it. According to the statement of the person with the communication disorder, the pictogram is placed under a scale at the top of the mat with pictograms for positive, not sure and negative. Hereby you receive insight in the opinions of a person about a specific topic. Because of the pictograms, the understanding of spoken language is supported by the picture. Furthermore the understanding is supported by the written word on the cards that goes along as a subscript on the pictograms. By placing the cards on the mat it is possible to see the development of the whole conversation. This is especially helpful for persons with memory disorders.
The aim of the study was threefold: 1) to observe the effect of TM on shared decisions in communication with people with AD; 2) to assess if TM affects the use of language by people with AD in conversation; 3) to get insight in the usability of the Dutch version of TM for persons with AD and their relatives.

Method

A cross-over study was conducted. Therefor the Talking Mats manual and pictogram subscripts were translated from English into Dutch (part I).

Translation

Pictograms which are used for Talking Mats were translated into Dutch by the use of the backward-translation method. There for the English words were translated into Dutch. After that the words were again translated, now from Dutch into English. The aim was to check whether the chosen translation agrees with the original meaning in English (Goldfarb et.al., 2006).

Participants

For the study the participants were identified by contacting four nursing homes and a dementia self-help group in the area of Heerlen and Roermond. The aim was to involve six couples with each a person with AD and a family member of this person. The number of persons was limited to six couples because the study was carried out as a bachelorthesis. At least all couples which fulfilled the inclusion criteria were identified at three nursing homes. Especially the family members were interested in participation.

Inclusion criteria were: All persons with AD had to be in stage one or two of their disease following the categorization of the Communication Difficulties Questionnaire, which is based on communication aspects. The Communication Difficulties Questionnaire was also used to categorize participants with dementia for earlier studies regarding the original English version of Talking Mats. This is a list of questions about the communication abilities giving an indication of the stage of the disease. The Communication Difficulties Questionnaire was filled in by the family members of the persons with AD who agreed to take part in the study (informed consent).

Persons with AD who did have a severe impaired vision were excluded because otherwise they would not be able to see the pictograms. Also persons with other cognitive problems besides these caused by AD were excluded.
The participants of the study were contacted by e-mail and by telephone at nursing homes.
An application by the ethic commission was accepted. Pseudonymization was used to protect the identity of the participants.

Training for the participants

The researchers followed a training about how to use Talking Mats properly. The time of the training was different for the two groups. This will be explained under the section ‘measurements’. Each couple in this study received an explanation about Talking Mats by the researchers in their room in the nursing home. The use of Talking Mats was demonstrated and the participants had the time to explore the use of Talking Mats and to ask questions of the researchers. After that the participants had two weeks to practice the use of Talking Mats with their family member with AD before the measurement with Talking Mats took place. Each couple got a Talking Mats set for practice and for using it at the three measurement moments.

Measurements

The six couples were divided at random into two groups of each three couples. Each couple had three conversations with regard to planning daily activities, one with Talking Mats and two without. The three conversations of the six couples with and without TM were filmed with consent of all participants.

After the baseline measurement, the measurements followed the cross-over design of the study (Tab. 1). This means that in group one the participants first had a measurement with Talking Mats and then a measurement without Talking Mats. In group two it was the other way around.

Table 1: Measurements

	Group 1	**Group 2**
Baseline measurement	Conversation without Talking Mats (OPTION Scale) Scoring on Communication	Conversation without Talking Mats (OPTION Scale) Scoring on Communication

	Difficulties Questionnaire	Difficulties Questionnaire
1st measurement	Conversation with Talking Mats (OPTION Scale)	Conversation without Talking Mats (OPTION Scale)
2nd measurement	Conversation without Talking Mats (OPTION Scale)	Conversation with Talking Mats (OPTION Scale)

The cross-over design was used to make comparisons possible for this quite small number of participants. At the baseline measurement the participants did not receive any information and explanation about Talking Mats. This measurement at baseline was used as point of comparison for later measurements. The participants got the training about Talking Mats at the meeting before the measurement with Talking Mats. In group one this took place after the baseline measurement and in group two this happened after the first measurement. Then the measurement with Talking Mats took place.
The measurements took place with an interval of two weeks. After the measurements, the videos where analyzed referring to the process of shared decision-making and typical language aspects of AD. Shared decisions were analyzed by using the OPTION Scale.

Interview with participants
A qualitative study took place to get insight into the perspective of the participants with regard to their experience in the use of Talking Mats. At first semi-structured interviews took place after the baseline measurement to get insight in the perceived difficulties in communication of the participants. A second semi-structured interview took place after the measurement with Talking Mats. The interviews took place in the room of the participants at the nursing homes. The two researchers interviewed all couples. All participants, persons with and without AD, were asked for their own perspective during the interviews. To support the communication with the persons with AD, pictograms, for example for ‘yes’ or ‘no’, were used as well as pen and paper by the persons with AD for which it sometimes was easier to read than to understand spoken language.

At the baseline measurement the researchers wanted to know how the line of conversation was, whether there are problems that often occur in conversation between family member and person with AD, which kind of problems often can be noticed during conversation with each other and how family members do try to deal with communication problems (strategies or aids).

After the conversation with Talking Mats, the participants were also asked what they think about the use of Talking Mats. During this interview, the participants were asked how it is to use Talking Mats (whether the pictograms are attractive, if the manual is helpful and easy to understand etc.), whether the participants noticed an effect of Talking Mats on the conversation and if there are points that need to be improved. The interviews were recorded and afterward transcribed.

Analysis

Shared decisions
The hypothesis for the first assumption was that shared decisions increase because of the use of Talking Mats. This was assessed by the use of an observation list called OPTION Scale.

The OPTION Scale is an accepted observation instrument for the process of shared decision-making with a good inter-rater reliability (0.50-0.85) (Elway, 2003; Elwyn et.al., 2011). This list exists of 12 items. Each item can be scored on a scale between 0 and 4. Thus the maximum score is 28. Per number a definition, sometimes even an example is given which makes it easier to score the observed behavior. As higher the score as better is the use of shared decision-making.

The OPTION was filled in for each conversation by an external blinded examiner who did not get any information about the use and the effect of Talking Mats. Afterward, two conversations, one with and one without the use of Talking Mats, were rated by two other external blinded examiners to check if the scores on the OPTION for these conversations were comparable between the three examiners. The aim was to prove the inter-rater reliability of this study. The scores on the OPTION Scale for the conversations with Talking Mats were later compared to the scores for the conversations without Talking Mats. The correlation coefficient for the inter-rater reliability was positive with r=1 and a p-value of 0.01.

Then the scores on the OPTION Scale for each measurement were analyzed with a t-test for dependent groups in SPSS. Therefor the results of the baseline measurement and the measurements without Talking Mats were each compared with the results of the measurement with Talking Mats for each of the two groups.

Language aspects

The hypothesis as regards the language aspects was that seven typical language aspects of AD are reduced because of the use of Talking Mats.
Based on the videos of the measurements, the whole conversation was transcribed verbatim to analyze seven typical aspects of language by the participants with AD which can be seen in the following table (Dijkstra et.al., 2004).

Table 2: Language Aspects (relevant for the analyzation)

language aspect	description
disruptive topic shift	suddenly switching to another topic of conversation
empty words	words that do not carry any information
repetitions	repeating a word or a phrase
perseverations	sticking in a certain phrase or word that is often repeated
semantic paraphrases	using a word with a related meaning e.g. 'tree' instead of 'flower'
phonematic paraphrases	using a word that sounds similar e.g. 'root' instead of 'mood'
word-finding difficulties	if a person needs more time to find the correct word or is even not able to find it

These seven different language aspects were counted for all turns of the participants with AD per conversation. Then a percentage for each language aspect was calculated relying on the whole number of turns during the conversation. The percentage of each language aspect was compared between the conversations with and without Talking Mats. The aim was to explore whether Talking Mats had an effect on the language use of the participants with AD.

The percentages were analyzed with a t-test for dependent group in SPSS. For this aim the measurements with Talking Mats were first compared with the baseline measurement and then with the measurement without Talking Mats for the two groups.

Usability of the Dutch version of Talking Mats

The interviews with the participants were transcribed verbatim. Afterward the answers of the participants were structured under themes, for example 'use of communication strategies' or 'usability of Talking Mats'. The researchers examined the data independently for all interviews. Then they checked whether there was agreement between them and discussed discrepancies.

Results

Six couples could be recruited for this study. They were all in stage two of the disease and between 84 and 90 years old. Five women with AD and one man took part in the study together with her daughters.

The first result of this study was a Dutch version of Talking Mats, adapted for persons with dementia and their relatives. The version included an adapted manual, two sets with pictograms (coloured Picture Communication Symbols and black-white Sclera pictograms), a mat to place the pictograms and a DVD with videos that show the use of Talking Mats. The manual was condensed to adapt it to the target group. In the semi-structured interviews the participants stated that this version of Talking Mats was easy to use and that the handbook gave a good instruction about how to use Talking Mats. Some found it even pleasurably to use this communication aid. All participants choose the Picture Communication Symbols because they were seen as more attractive.

Effect of Talking Mats on shared decisions

The analysis of the observation list OPTION showed a significant increase of the practice of shared decisions for nearly all conversations with Talking Mats.

Table 3: Results for the OPTION-Scale (Group 1)

Group 1	Baseline Measurement	Measurement 1 (without TM)	Measurement 2 (with TM)
Participant 1	18	11	28
Participant 2	9	8	25
Participant 3	3	3	25

Table 4: Results for the OPTION-Scale (Group 2)

Group 2	Baseline Measurement	Measurement 1 (with TM)	Measurement 2 (without TM)
Participant 4	11	25	9
Participant 5	9	22	6
Participant 6	13	26	-

Table 5: Test for paired samples (OPTION Scale)

Test for paired samples

			paired differences							
						95% Confidence interval				
			Mean	Standard deviation	Standard error	lower	upper	T	df	Sig. bilateral
Pair 1	Result 1.1 -	Result 2.2	-980,20500	1233,01745	871,87500	-12058,42725	10098,01725	-1,124	1	,463
Pair 2	Result 1.0 -	Result 1.1	5,55333	7,88620	4,55310	-14,03707	25,14374	1,220	2	,347
Pair 3	Result 1.0 -	Result 1.2	-33,33000	12,50000	7,21688	-64,38172	-2,27828	-4,618	2	,044
Pair 4	Result 1.1 -	Result 1.2	-38,88333	6,01599	3,47333	-53,82788	-23,93879	-11,195	2	,008
Pair 5	Result 2.0 -	Result 2.1	-2777,66667	119,80122	69,16727	-3075,26941	-2480,06393	-40,159	2	,001
Pair 6	Result 2.0 -	Result 2.2	1083,50000	942,57334	666,50000	-7385,18546	9552,18546	1,626	1	,351
Pair 7	Result 2.1 -	Result 2.2	3895,50000	795,49513	562,50000	-3251,74016	11042,74016	6,925	1	,091

(1.0. = group 1 baseline measurement, 1.1 = group 1 1st measurement, 1.2. = group 1 2nd measurement, 2.0. = group 2 baseline measurement, 2.1. = group 2 1st measurement, 2.2. = group 2 2nd measurement)

There was a significant difference in group one between the baseline measurement and the second measurement moment when Talking Mats was used in the conversation (t (2) = - 4,618, p< 0.044). There was also a significant difference in group one between measurement 1 (without TM) and measurement 2 (with TM) (t (2) = - 11,195, p< 0.008). In group two there also appeared a significant difference between the measurement at baseline and the measurement with TM (t (2) = - 40,159, p< 0.001). There was a drop out in group two at the last measurement because of a longer disease (pneumonia with coma) of the one participant with AD. It is possible that because of the drop out there was no significant difference between measurement 1 (with TM) and measurement 2 (without TM) (t (1) = 6,925, p< 0.91). However three of the four comparisons revealed a significant increase of shared decisions. The persons with AD were more involved in conversation and most of all they were more included in the process of making decisions. This result agrees with the answers of the participants by the interviews. Most of the participants mentioned that because of Talking Mats they got to know more about the thoughts of their relative.

Effect of Talking Mats on the language use of the participants with AD

The seven language aspects were analyzed for each participant with AD. The results can be seen in Tab. 6 to 11.

Table 6: Use of Seven Relevant Language Aspects by Participant 1

Language aspect	Baseline (in %)	1st measurement (in %)	2nd measurement (in %)
disruptive topic shift	12,59	11,74	6,20
empty words/phrase	5,40	3,21	1,24
repeating	3,24	2,14	5,79
perseveration	2,88	2,49	0
paraphrases (semantic)	0,36	2,49	0,41
paraphrases (phonematic)	0	0	0
word-finding difficulties	4,32	5,69	0,41

Table 7: Use of Seven Relevant Language Aspects by Participant 2

Language aspect	Baseline (in %)	1st measurement (in %)	2nd measurement (in %)
disruptive topic shift	3,18	10,40	2,95

empty words/phrase	0	0	0
repeating	6,37	6,5	12,35
perseveration	0	0	0
paraphrases (semantic)	0,64	0	0
paraphrases (phonematic)	1,30	1,30	0
word-finding difficulties	1,30	7,70	0,59

Table 8: Use of Seven Relevant Language Aspects by Participant 3

Language aspect	Baseline (in %)	1st measurement (in %)	2nd measurement (in %)
disruptive topic shift	1,95	5,42	1,05
empty words/phrase	0	0	0
repeating	9,74	10,84	10
perseveration	0	0,99	0
paraphrases (semantic)	0	0	0
paraphrases (phonematic)	0	0	0
word-finding difficulties	0	0	0

Table 9: Use of Seven Relevant Language Aspects by Participant 4

Language aspect	Baseline (in %)	1st measurement (in %)	2nd measurement (in %)
disruptive topic shift	5,78	1,84	8,27
empty words/phrase	6,36	0	7,52
repeating	2,89	0	1,50
perseveration	5,21	1,84	9,02
paraphrases (semantic)	0	0	0
paraphrases (phonematic)	1,73	0	0
word-finding difficulties	13,29	3,67	1,50

Table 10: Use of Seven Relevant Language Aspects by Participant 5

Language aspect	Baseline (in %)	1st measurement (in %)	2nd measurement (in %)
disruptive topic shift	21,21	9,56	13,43
empty words/phrase	6,06	3,68	4,48
repeating	1,52	1,47	0
perseveration	0	0	0
paraphrases (semantic)	0	0	1,49
paraphrases (phonematic)	1,52	0,74	0
word-finding difficulties	16,67	5,88	8,96

Table 11: Use of Seven Relevant Language Aspects by Participant 6

Language aspect	Baseline (in %)	1st measurement (in %)	2nd measurement (in %)
disruptive topic shift	8,13	6,89	-
empty words/phrase	4,88	1,77	-
repeating	0,82	1,59	-
perseveration	0	0	-

paraphrases (semantic)	0	0	-
paraphrases (phonematic)	0,82	0	-
word-finding difficulties	7,32	3,71	-

The statistical analysis of the use of language of the participants with AD showed no significant differences between the conversation with and without Talking Mats for the two groups. There was no overall improvement referring to one of the seven language aspects but only individual differences.

The participants, especially the family members, stated that there were communication problems between them and their relatives with AD at the beginning of the study. Most of all the understanding of each other was mentioned, even by four of the participants with AD. One family member said about her father: “Sometimes he says things that I don’t really understand.”

Also, the absence of the persons with AD during a conversation is a big problem for many family members. Three participants without AD make use of photo books to support the memory during a conversation. This strategy is also a way of finding something to speak about, because family members mentioned in the interviews that it can be difficult to find a topic of conversation.

In matters of the Dutch version of Talking Mats, all the participants mentioned that it is easy to use. Also the manual was a good support to practice the use of this communication framework. The participants especially mentioned the positive effect of the pictograms on the understanding of each other.

Some of the participants, even two persons with AD, stated, that Talking Mats made it possible to get to know more about the thoughts of each other. A woman with AD said during the interview: “I can present more of my thoughts.”

Two family members even mentioned that Talking Mats is a possibility to involve her parent with AD in making decisions. A family member stated during the interview: “Now I see how many decisions are made for my mother although she is still able to do this.”

However two of the participants without AD were not sure about the effect of Talking Mats on the communication. They considered that this could be because they did not have much experience in using Talking Mats. A woman with AD stated: “I think it is not a bad idea. Perhaps I have to practice more to notice if there is an effect?”

Conclusion

First, the aim of this study was to find out whether Talking Mats increases shared decisions in conversations between persons with AD and a relative. The second aim was to assess if the occurrence of seven for AD typical language problems can be reduced by the use of Talking Mats in conversations between persons with AD and a relative. The last purpose of this study was to discover, whether the Dutch version of Talking Mats, which was developed for this research, is easy and pleasant to use. Research has already been conducted with regard to the use of the original English version of Talking Mats with different groups of people with a communication problem, for example aphasia, mentally disabled and also dementia. Different studies proved that the English version of Talking Mats is an appropriate communication framework, which is especially adequate to support the process of shared decision-making (Cox et.al., 2007; Cox et.al., 2009; Cox et.al., 2010; Murphy, 2010; Murphy

et.al., 2011). In this research the aim was to find out, whether this can also be said about the Dutch version of Talking Mats.

Strengths and limitations

During the research it was not always possible to do everything as planned. It was difficult to find adequate participants for this study. The participants for this research were living in different nursing homes. Because of that it was not possible to give a group-training for all participants so that they could practice and discuss with each other. The training had to be given for each couple individually. So it could be possible that the effect of the training was not optimal. In the interviews three participants stated that they felt not certain enough to use Talking Mats. Practising with and learning from each other could have had a positive influence on the results. In this study the participants got an explanation and demonstration and then had to practice on their own. Perhaps this caused uncertainties and even discrepancies to the way in which Talking Mats should be used. The original version of Talking Mats was mentioned to be used only by professionals (Cox et.al., 2010). In this study the participants were caregivers without the expertise of a professional. Thus more training in the use of Talking Mats and most of all more practising with other family members should have been better. However this research revealed positive results.

The most important result of this study relates to the applicability of the Dutch version of Talking Mats, which as the original English version would suggest, leads to an increase in shared decision-making practices (Cox et.al., 2009; Cox et.al., 2010). Indeed, Talking Mats can be a useful support to involve persons with AD in making decisions about daily activities but also in decisions about their care (Cox et.al., 2007). Unfortunately it was not possible to state whether Talking Mats has an effect on the use of language of persons with AD. It would be interesting to get insight in how Talking Mats works and where it affects communication. A possibility could be to investigate if Talking Mats has an effect on the speech comprehension of persons with AD. Further research on this topic would be required.

Clinical implications

The Dutch version of Talking Mats, which was developed for this research, makes it possible to use Talking Mats properly in the Netherlands. This was not possible before, because the written words under the pictograms were in English. Also the manual is now available in Dutch. This makes it easier for the users of Talking Mats to get to know how they have to use this communication framework.

The use of Talking Mats in nursing homes, in activity centers, at home or at other places could be helpful to support communication with people with AD, for example, to communicate about daily activities, or more severe considerations such as total parenteral nutrition or intravenous feeding. The quality of care for persons with AD may improve by the use of Talking Mats because persons with AD are supported in expressing their wishes. The benefits of using Talking Mats were already investigated in UK and appear to be mirrored by the Dutch version of Talking Mats. However, these benefits assume the correct use Talking Mats by people with AD and their caregivers.

References

Bridges, J. & Wilkinson, C. (2011). Achieving dignity for older people with dementia in hospital. *Nursing Standard, 25 (29),* 42-47.

Byrne, K. & Orange, J. B. (2005). Conceptualizing communication enhancement in dementia for family caregivers using the WHO-ICF framework. *International Journal of Speech-Language Pathology, 7* (4)*,* 187-202.

Cox, S., Gray, C. & Murphy, J. (2007). The use of Talking Mats to improve *communication and quality of care for people with dementia. Housing, Care & Support*, *10* (3), 21-27.

Cox, S., Gray, C. & Murphy, J. (2009). Talking Mats: the effectiveness of a low technology communication framework to help people with dementia to express their views. *Journal of Assistive Technologies, 1* (2)*,* 30-34.

Cox, S., Murphy, J. & Oliver, T. (2010). 'She can see how much I actually do!' Talking Mats®: helping people with dementia and family carers to discuss managing daily living. *Housing, Care & Support, 13 (3),* 27-35.

Dalemans, R., De Witte, L., Beurskens, S., van den Heuvel, W., & Wade, D. (2010). An investigation into social participation of people with aphasia. *Disability and Rehabilitation, 32* (20), 1678-1685.

Dijkstra, K., Bourgeois, M.S., Allen, R.S. & Burgio, L.D. (2004). Conversational coherence: discourse analysis of older adults with and without dementia. *Journal of Neurolinguistics, 17* (4*),* 263-283.

Elwyn, G., Edwards, A., Wensing, M., Hood, K., Atwell, C. & Grol, R. (2003). Shared decision making: developing the OPTION scale for measuring patient involvement. *Quality and Safety in Health Care, 12,* 93-99.

Elwyn, G., Loon, K., Scholl, I. & Sepucha, K. (2011). Measurement of shared decision making – a review of instruments. *Zeitung für Evidenz, Fortbildung und Qualität im Gesundheitswesen, 105,* 313-324.

Francke, A., Peeters, J., Spreeuwenberg, P., Van Beek, S. & Zwaanswijk, M. (2009). Motieven en belasting van mantelzorgers van mensen met dementie. Resultaten van de peilingen met de monitor van het Landelijk Dementieprogramma*, (from http://www.nivel.nl/sites/default/files/bestanden/Factsheet-Belasting-mantelzorgers-bij-dementie.pdf*).

Goldfarb, N*. &* Grunwald, D. (2006). Back Translation for Quality Control of Informed Consent Forms. *Journal of Clinical Research Best Practices, 2* (2).

Härter, M., Hölzel, L., Kriston, L., Loh, A., Scholl, I. & Simon, D. (2010). The 9-item Shared Decision Making Questionnaire (SDM-Q-9). Development and psychometric properties in a primary care sample. *Patient Education and Counseling, 80,* 94-99.

MacRae, H. (2011). Self and other: the importance of social interaction and social relationships in shaping the experience of early-stage Alzheimer's disease. *Journal of Aging Studies, 25*, 445-456.

Menne, H. & Whitlatch, C. (2009). Don't Forget About Me! Decision Making by People with Dementia. *GENERATIONS – Journal of the American Society on Aging, 33* (1),66-73.

Murphy, J., Gray, C.M., Van Achterberg, T., Wyke, S. & Cox, S. (2010). The effectiveness of the Talking Mats framework in helping people with dementia to express their views on well-being. *Dementia, 9* (4)*,* 454-472.

Murphy, J. & Strachan, Y. (2011). Talking Mats®: Extending the reach into goal setting practices for Health and Social Care Staff in Edinburgh, *University of Stirling.*

Sury, L., Burns, K. & Brodaty, K. (2013). Moving in: adjustment of people living with

dementia going into a nursing home and their families. *International Psychogeriatric*, 1-10.

Van Gorp & B., Vercruysse, T. (2012). Frames and counter-frames giving meaning to dementia: A framing analysis of media content. *Social Science & Medicine, 7*, 1274-1281.

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