

Dement Geriatr Cogn Disord Extra 2018;8:453-466

DOI: 10.1159/000494660 Received: July 10, 2018 Accepted: October 16, 2018 Published online: December 6, 2018

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Original Research Article

Can the Mixed Virtual Reality Simulator Into D'mentia Enhance Empathy and Understanding and Decrease Burden in Informal Dementia Caregivers?

Linda Helena Jütten Ruth Elaine Mark Margriet Maria Sitskoorn

Department of Cognitive Neuropsychology, Tilburg University, Tilburg, The Netherlands

Keywords

 $Care giving \cdot Informal\ care giving \cdot Experiential\ learning \cdot Dementia \cdot Intervention \cdot Simulation\ training \cdot Technology$

Abstract

Objective: To evaluate whether the mixed virtual reality dementia simulator training Into D'mentia increased informal caregivers' understanding for people with dementia, their empathy, sense of competence, relationship quality with the care receiver, and/or decreased burden, depression, and anxiety. Methods: A quasi-experimental longitudinal study with an intervention group (n = 145) and a control group (n = 56) was conducted. All participants were informal caregivers of people with dementia. They completed six questionnaires and semistructured interviews 1 week before as well as 1 week, 2.5 months, and 15 months after the training. Data were analyzed on both group and individual level using linear mixed model analyses and Reliable Change Indices. Results: Eighty-five percent of the participants in the intervention group found the intervention useful; 76% said they had changed their approach to caregiving, and 61% stressed that the intervention had increased their understanding of dementia. No significant differences were found between the two groups over time regarding empathy, sense of competence, relationship quality with the care receiver, burden, depression, and anxiety, at either group or individual level. **Conclusion:** Caregivers indicated that the Into D'mentia intervention improved their understanding of dementia, that they had learned to be more patient, to take things more slowly, and to focus on positive aspects of caregiving. However, no significant change was found on the variables assessed via the questionnaires. Future research can consider enriching this intervention with other aspects such as more educational material, more simulations, and group sessions, tailored to the individual caregiver







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and his/her situation, and examine whether these new interventions yield change on questionnaires. These new, more personalized interventions for dementia caregivers could help caregivers to better understand the persons with dementia they care for and to ultimately enhance the well-being of both caregivers and persons with dementia.

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Introduction

Caregiving can be very burdensome for informal caregivers of people with dementia and may lead to various deleterious consequences, including poorer psychological health [1]. In order to diminish these negative effects, several interventions have been developed [2]. However, few interventions have attempted to increase the caregiver's understanding of and empathy for people with dementia in an attempt to reduce burden, while the benefits of increasing both are thought to be beneficial for professional and informal carers [3–6] and for the person they care for [6, 7]. The mixed virtual reality Into D'mentia simulator [8], developed in 2010, aims to fill this research gap.

Understanding and knowledge of dementia enable caregivers to deliver high-quality care; they are essential for caregivers to be able to meet the patient's health care needs [6] and can diminish communication problems between the caregiver and the person with dementia [9]. This could in turn reduce caregiver burden and improve relationship quality [10]. Existing interventions have mostly focused on enhancing knowledge and utilized written materials as well as information about coping strategies. Overall, these interventions are only moderately effective in alleviating burden and depression [11]. Caregivers may need more understanding (instead of only knowledge) to accurately appreciate the patients' experience of the problem and in turn be able to meet the patient's health care needs. To reach a higher level of understanding, caregivers might need to look at things from the person with dementia's perspective [6]. This links to cognitive empathy – the ability to understand the other persons' perspective, or theory of mind - and (to a lesser extent) to affective empathy - feeling what another person feels [4]. Cognitive and affective empathy may have different influences on aspects of well-being of informal dementia caregivers. Cognitive empathy has been positively associated with lower stress appraisal, lower threat appraisal, and lower levels of depression among informal caregivers [5, 12]. Affective empathy has been found to be associated with higher stress appraisal, less life satisfaction, and more anxiety symptoms [5, 12]. These findings suggest that, in addition to enhancing understanding, the intervention's focus should be on enhancing cognitive empathy (and/or reducing affective empathy) to enhance the caregivers' lives.

To date, only two interventions are (partially) aimed at heightening caregivers' empathy: the web-based STAR (Skills Training and Reskilling) e-learning course [13] and the 13-min virtual reality movie of Through the D'mentia Lens (TDL) [14], both of which were moderately effective in heightening (cognitive) empathy. However, both studies used small study samples, and the study about the TDL intervention omitted a control group. While the results are promising, no thorough (longitudinal) study incorporating both an intervention and a control group has attempted to heighten the understanding of and empathy for persons with dementia in order to enhance the caregivers' lives.

In 2010, the mixed virtual reality simulator Into D'mentia was developed, in which dementia caregivers experience what it is like to have dementia [8]. The simulator's goal is to increase the understanding of and empathy for people with dementia in informal caregivers by experiential learning. Experiential learning is learning in which the learner is directly in touch with the realities being studied, instead of only reading, hearing, or writing about it





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[15], and can be achieved by (virtual or augmented) simulation [16]. Simulation training to enhance understanding and empathy has been found to be effective for health care students [17], but has to date not been thoroughly studied in experimental studies with informal caregivers.

The primary aim of the current study was to examine whether the Into D'mentia training increased understanding of dementia and cognitive empathy (1 week, 2.5 months, and 15 months after the intervention) in informal caregivers. The secondary aims were to examine whether the Into D'mentia training decreased caregiver burden, depression, and anxiety, and/or enhanced sense of competence and relationship quality with the care receiver. However, the caregiver population is very heterogeneous; caregivers differ from each other on a number of caregiver-related variables (e.g., age, sex, educational level), care receiver variables (e.g., time since diagnosis), and background variables (e.g., time spent on caregiving, whether or not they live with the care receiver). In addition, caregivers differ in their baseline empathy levels. Due to the heterogeneous nature of the group we did not expect the intervention to have the same effects for every caregiver, therefore both group and individual analyses were executed.

Design and Methods

Study Design

The current study is a quasi-experimental longitudinal investigation into the effectiveness of the Into D'mentia simulator. The outcome variables were assessed at four time points: 1 week before the Into D'mentia training (T1), 1 week after the training (T2), 2.5 months after the training (T3), and 15 months after the training (T4) to examine both shortand long-term effects. The published protocol of the study [18] describes the method in greater detail.

Participants

An intervention and a control group, group-matched on sex and level of education, took part. All participants were adult informal caregivers (who spent at least 8 h per week on caregiving) of a relative, spouse, or friend with dementia who lived at home. The inclusion and exclusion criteria were the same for both groups, while the controls (an attention-only group) did not experience the simulator training. None of the participants or their care receivers were prohibited from usual care.

The recruitment of the intervention group started in July 2014 and ended in August 2014, during which time 192 participants were screened for eligibility and 145 were included. One participant did not complete T2 and 20 participants did not complete T3. At T4, 80 participants dropped out, leaving 65 participants at the final time point. The recruitment of the control group started in May 2015 and ended in January 2017, during which time 75 participants were screened for eligibility and 56 were included. Three participants did not complete T2, and 13 participants did not complete T3. At T4, 34 participants dropped out, leaving 22 participants at the final time point. The participants who did not complete an assessment without giving reasons why were invited to take part in the following measurement(s), so it is possible that a participant did not complete T2, but did complete T3. All available data were analyzed using linear mixed models analyses. Online supplementary Figure S1 (for all online suppl. material, see www.karger.com/doi/10.1159/000494660) shows the flowchart of participants.

Table 1 shows the participant characteristics and pre-intervention scores on the outcome variables. Mean age was 59.6 (SD = 11.9) years in the intervention group and 63.8 (SD = 11.8)





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Table 1. Participant characteristics

	Intervention group (n = 145)	Control group (n = 56)	Test value ^a	p value
Characteristics of the informal caregivers				
Age, years	59.6±11.9	63.8±11.8	2.250	0.026*
Male sex	30 (20.7%)	13 (23.2%)	0.153	0.704
Level of education ^b		- ()		
Low	23 (15.9%)	7 (12.5%)	0.407	0.816
Medium	52 (35.9%)	20 (35.7%)		
High	70 (48.2%)	29 (51.8%)		
Time providing care a week, h	47.2±60.1	78.6±65.4	-3.232	0.001**
Relationship with the care receiver	17.12=00.12	, 0.0=00.1	0.202	0.001
Spouse	52 (36.1%)	30 (53.6%)	7.415	0.025*
Child	67 (46.5%)	23 (41.1%)		****
Other	25 (17.4%)	3 (5.3%)		
Cohabiting with the care receiver	46 (32.2%)	32 (57.1%)	10.532	0.002**
Characteristics of the persons with dementia				
Age, years	78.8±8.4	78.1±8.0	-0.551	0.583
Male sex	61 (42.7%)	26 (47.3%)	0.344	0.632
Dementia diagnosis	01 (42.7 70)	20 (47.370)	0.544	0.032
Alzheimer's dementia	86 (59.3%)	30 (58.8%)	2.150	0.708
Vascular dementia	23 (15.9%)	12 (23.5%)	2.100	0.7 00
PD	3 (2.1%)	1 (2.0%)		
Other	8 (5.5%)	2 (3.9%)		
No differential diagnosis	25 (17.2%)	6 (11.8%)	1.007	0.050
Time since diagnosis, years	3.6±2.6	2.6±2.2	1.907	0.058
Pre-intervention scores on the questionnaires				
IRI – Perspective Taking ^c	17.7±4.0	17.4±4.4	0.498	0.619
IRI – Empathic Concern ^c	17.8±4.3	17.8±3.9	-0.026	0.980
HADS-D ^d	4.8±4.2	5.5±3.5	-1.113	0.268
HADS-A ^d	6.2±3.8	7.8±4.3	-2.672	0.008**
CRA – Disruption ^e	2.9±0.9	3.5 ± 0.8	-4.303	<0.001**
CRA – Health ^e	2.4±0.8	3.0 ± 0.9	-4.609	<0.001**
CRA – Support ^e	2.3±0.6	2.7±0.8	-3.358	0.001**
CRA – Self-Esteem ^e	3.8±0.6	3.7 ± 0.6	1.139	0.256
CRA – Finances ^e	2.3±0.6	2.6±0.8	-2.493	0.014*
RQI ^f	31.6±7.9	29.4±8.7	1.637	0.103
QoR – Current ^g	13.2±2.9	13.4±3.0	-0.393	0.695
SSCQ ^h	27.3±5.0	24.1±5.5	3.851	<0.001**

Values are presented as mean \pm SD or n (%). CRA, Caregiver Reaction Assessment; HADS, Hospital Anxiety and Depression Scale; IRI, Interpersonal Reactivity Index; PD, dementia associated with Parkinson's disease; QoR, Quality of Relationship; RQI, Relationship Quality Index; SSCQ, Short Sense of Competence Questionnaire. ^a Test values for continuous outcomes: t values for normally distributed variables and standardized statistics for Mann-Whitney U-tests for non-normally distributed variables; for categorical values: Pearson χ^2 values. ^b Educational level according to Verhage [35], recoded as low (1–4), medium (5), or high (6–7). ^c Score range 0–28. ^d Score range 0–21. ^e Score range 1–5. ^f Score range 7–42. ^g Score range 4–20. ^h Score range 7–35. *p < 0.05, **p < 0.01.

years in the control group, which is a small but significant difference (p = 0.026). Most participants were female (79.3% in the experimental group and 77.8% in the control group), and most were highly educated (48.3% in the experimental group and 51.8% in the control group). The groups did not differ on these latter two sociodemographic variables. However, participants in the control group spent significantly more time a week on providing care (p = 0.026).





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0.001), more of them lived with their care receiver (p = 0.002), and the control group consisted of a higher proportion of spouses than the intervention group (p = 0.025).

There were no differences on the sociodemographic variables between those who completed T3 and those who dropped out before T3 in either group. Regarding the outcome variables, participants of the intervention group who dropped out had significantly higher anxiety scores at T1 than those who completed T3 (mean = 8.3, SD = 3.8 versus mean = 5.8, SD = 3.7, p = 0.004), and they had better perceived social support (Caregiver Reaction Assessment – Support) (mean = 1.9, SD = 0.9 versus mean = 2.3, SD = 0.8 p = 0.035). Regarding the control group, the participants who completed T3 had significantly fewer health problems (Caregiver Reaction Assessment – Health) than those who dropped out before T3 (mean = 2.8, SD = 0.9 versus mean = 3.6, SD = 0.8, p = 0.024). No other significant differences between those who did and did not complete T3 were found. Online supplementary Table S1 shows all comparisons.

There were no differences on the sociodemographic or outcome variables between the participants who completed T4 and those who dropped out before T4 in the intervention group. Regarding the control group, the participants who completed T4 had significantly fewer financial problems at T1 than those who dropped out before T4 (mean = 2.4, SD = 0.9 versus mean = 2.9, SD = 0.7, p = 0.039). No other differences were found. Online supplementary Table S2 shows all comparisons.

Intervention

The intervention consisted of a mixed virtual reality dementia simulator training, an individual conversation with the trainer immediately after the simulation, and a group meeting with 8–10 other participants 1–2 weeks later. In the simulator, the participants experienced what it is like to have dementia, as if they walked in the patients' shoes. During the group meeting, the experiences in the simulator were shared and put in perspective. In addition, practical tips and tricks were shared, and the caregivers could learn from each other's caregiving experiences. The control group was an "attention only" group and received no intervention. The protocol describes the intervention in greater detail [18].

Outcome Measures

Semi-Structured Interview. During the semi-structured interviews at T3 and T4, several questions were asked (to the intervention group only) about the overall experienced usefulness of the intervention, whether the caregivers' understanding of the person with dementia had changed, and whether the caregivers had learned anything from the intervention (Table 2).

Questionnaires – Empathy. Two subscales of the Interpersonal Reactivity Index (IRI) [19] were used to measure empathy: Perspective Taking and Empathic Concern. Perspective Taking measures cognitive empathy, the tendency to take the psychological point of view of others, akin to the "theory of mind" concept (Cronbach's $\alpha = 0.670$). Empathic Concern measures affective empathy, the ability to feel for others (Cronbach's $\alpha = 0.655$). Both subscales consist of seven items, each rated on a five-point Likert scale (0–4), with a maximum score of 28 per subscale [20].

Questionnaires – Secondary Outcome Measures. The other outcomes were caregiver burden, measured using the Caregiver Reaction Assessment [21], subscales Impact of Caregiving on Disrupted Schedule, Health Problems, Lack of Family Support, Self-Esteem, and Financial Problems; depression and anxiety, both measured using the Hospital Anxiety and Depression Scale [22]; relationship quality, measured with both the Relationship Quality Index [23] and the Quality of Relationship – Current [24]; and sense of competence, measured with the Short Sense of Competence Questionnaire [25].





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Table 2. Results of the interview (at T3 and T4)

		T3, %	T4, %
Simulator			
Does the simulator give an accurate reflection of what a	yes	82.2	79.7
person with dementia goes through?	a bit	13.1	17.2
	no	4.7	3.1
Did the simulator meet your expectations?	yes	46.8	73.0
	a bit	18.8	20.7
	no	15.6	6.3
	I had no expectations	18.8	
Do you think the simulator is useful?	yes	85.2	87.1
	a bit	8.6	8.1
	no	6.2	4.8
Group meeting with other participants after the simula	ation		
Did you feel supported by the experiences and stories of	yes	79.0	62.5
the other participants in the group meeting?	a bit	14.0	29.7
	no	7.0	7.8
Did the group meeting meet your expectations?	yes	61.2	58.0
	a bit	24.0	38.7
	no	11.6	3.3
	I had no expectations	3.2	
Do you think the group meeting is useful?	yes	82.2	73.4
	a bit	11.6	23.4
	no	6.2	3.2
Whole training (simulator and group meeting combine	ed)		
Did the whole training (simulator and group meeting	yes	70.5	78.1
together) have a personal impact on you?	no	29.5	21.9
Do you think that the whole training helps you to be a	yes	65.9	46.8
more effective caregiver?	a bit	9.3	43.8
S .	no	24.8	9.4
Do you think the whole training has helped you to	yes	60.5	54.7
understand your spouse/relative/friend?	a bit	14.7	37.5
	no	24.8	7.8
Do you think that you are better prepared for what is	yes	37.2	35.9
going to happen in the future?	a bit	18.6	46.9
	no	44.2	17.2
Are you surer of your qualities because of the training?	yes	56.3	37.5
, - 2 5 a. o. o. , o a. quanties secure of the truming.	a bit	15.6	45.3
	no	28.1	17.2
Did you learn anything from the training?	yes	93.0	85.9
za jou zou n anjamig nom the truming.	no	7.0	14.1
Do you do anything different in caring because of the	yes	76.0	58.7
training?	no	24.0	41.3





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Study Procedure

All participants completed a semi-structured interview and a questionnaire booklet at each measurement point. Trained neuropsychologists, who were not part of the intervention, conducted the (individual) semi-structured interviews with the caregivers. Due to the content of the semi-structured interviews, the interviewers could not be blinded. However, participants filled out the questionnaires themselves at home, minimizing the interviewers' influence. The participants were blinded to the assigned groups; each groups were unaware of the other group's existence. The control group was debriefed after the last measurement and offered an educational group meeting to compensate for their contribution.

Statistical Analyses

Statistical analyses were performed using SPSS Statistics 22 [26] and R software, nlme package [27]. Differences between the groups on demographic variables and pre-intervention scores were examined using independent-samples t tests and χ^2 tests.

Semi-Structured Interview. The interview questions were analyzed using frequencies.

Questionnaires - Group Change. Comparative analyses between the two groups were conducted using linear mixed models analyses. For all outcome measures separate models were built using a step-up strategy [28]. The restricted maximum likelihood estimate (REML) was used to estimate the model parameters, and the Akaike Information Criterion (AIC) and the Bayesian Information Criterion (BIC) were used to estimate model fit. For each model, the random effect was the intercept, and the fixed effects were group (intervention versus control), time, and the time by group interaction. A quadratic effect of time was tested but found to be neither significant nor improving model fit, and therefore not included. No random slopes were added because these did not improve model fit. A first-order autoregressive covariance structure at level 1 and a scaled identity matrix at level 2 (because there was only one random effect) were selected because these provided the best fit. The groups were matched on sex and level of education, but differed significantly on the variables age, cohabiting with the care receiver, hours spent on care a week, and type of the relationship with the care receiver. These variables (accompanied by their interaction with time) were added consecutively to the full model (described above) to examine whether these improved the model fit. The model fit was estimated by computing the likelihood ratio statistic (using the log-likelihood based on the maximum likelihood and degrees of freedom) [28]. The final models included the covariates age, cohabiting with the person with dementia, and hours spent on care, since these models provided the best fit.

Questionnaires – Individual Change. The Reliable Change Index (RCI) was computed as an indication for clinically significant change [29], from both T1 to T2, T1 to T3, and T1 to T4. The RCI was based on a 90% CI, which corresponds to a cut-off value of 1.65. p values <0.05 were considered statistically significant. However, to adjust for multiple significance testing, the Benjamini-Hochberg procedure (false discovery rate) [30] was applied in case of significant results. This procedure is less strict than the Bonferroni correction and recommended for health-related studies [31].

Results

Semi-Structured Interview

Table 2 shows the answers and the questions asked during the semi-structured interviews with the caregivers in the intervention group at T3 and T4. At T3, most caregivers found the simulation and group meeting useful (85.2 and 82.2%, respectively); 65.9% thought that the training (simulator and group meeting combined) helped them to be a better caregiver;





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60.5% thought the training had helped them to better understand their care receiver; and 56.3% were surer of their qualities after the training. Ninety-three percent of the caregivers said they had learned something from the training. They indicated that they now had a better understanding of dementia and that they were more aware of the fact that they needed to be more patient with the care receiver. Seventy-six percent indicated that they did something different in caring for their loved one. The caregivers most often mentioned that after the intervention, they took things more slowly, that they had lowered their expectations of the care receiver, that they were learning to let go of disagreements rather than starting or continuing arguments, and that they focused more on the positive side of the caregiving experience and on the things that went well instead of focusing only on the losses.

Questionnaires - Group Change

Table 3 shows the means and SDs for all questionnaires on each time point and the results of the linear mixed models analyses. No significant differences were found between the groups over time for either primary outcome variable: Perspective Taking, β = 0.218, p = 0.381; Empathic Concern, β = 0.047, p = 0.862. For the secondary outcome variables, no significant results were found either.

Questionnaires - Individual Change

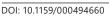
Tables 4 and 5 as well as online supplementary Table S3 show the RCIs for both groups and all outcome measures for T1–T2, T1–T3, and T1–T4, respectively. Approximately the same number of participants show "reliable change" (both "positively" and "negatively") on all outcome measures on all time intervals for both groups.

Discussion

The current study assessed whether the Into D'mentia simulator training could heighten empathy for, and understanding of, people with dementia among informal caregivers at both group and individual level. In addition, it examined whether the intervention could decrease symptoms of depression, anxiety, and burden, and/or enhance sense of competence and/or relationship quality between caregiver and care receiver. Most participants who underwent the intervention found it useful, indicated that it had helped to increase their understanding of dementia, and said that it had made them a more effective caregiver. However, no significant differences emerged between the two groups (intervention versus control) on the other outcome measures assessed via questionnaires.

For the caregivers who underwent the training, the understanding of dementia was heightened; almost all caregivers indicated that they had learned something from the training, and most also stated that they had changed the way they cared for the person with dementia. While social desirability response bias has to be taken into account when interpreting these findings, these results are promising because how caregivers experience caregiving is crucial and arguably more important than change on a questionnaire [32]. Heightening caregivers' understanding for people with dementia can be beneficial for both caregivers and people with dementia. For the people with dementia, caregivers' heightened understanding can lead to feelings of being important and to a better connection or relationship with the caregiver. In addition, adequate understanding of the problems of the person with dementia can enable the caregivers in meeting the patient's health care needs [6]. For the caregivers, enhanced understanding can lead to fewer communication problems [9], which in turn can lead to a better relationship and enhanced well-being. In addition, the caregivers claimed that they had changed the way they cared for the person with dementia, that they were taking things more





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Cognitive Disorders

p value 0.199 0.876 0.395 0.470 0.785 0.544 0.862 0.963 0.912 0.417 0.241 0.008 (0.18) -0.044(0.04)0.073(0.46)0.275 (0.38) 0.020(0.18)0.011(0.04)0.036(0.04)0.018(0.02)0.062(0.05)0.139(0.16)0.218 (0.25) 0.047 (0.27 β (SE) 28.9 ± 10.0 2.8 ± 0.8 24.0 ± 6.2 8.6 ± 4.2 8.4 ± 3.8 6.5 ± 3.6 8.8 ± 5.4 3.7 ± 0.6 3.2 ± 0.9 3.7 ± 0.7 3.0 ± 1.0 13.3 ± 3.6 **T**4 29.9±10.1 3.5 ± 0.8 2.7 ± 0.8 7.6 ± 4.2 2.9 ± 0.8 2.6 ± 0.9 13.4 ± 3.2 24.2 ± 5.4 17.9 ± 3.4 5.8 ± 4.0 3.6 ± 0.7 T3 2.7 ± 0.8 24.7±4.6 7.0 ± 3.6 17.2 ± 3.8 6.0 ± 4.0 7.5 ± 4.3 3.0 ± 0.9 3.6 ± 0.6 2.7 ± 0.9 3.8 ± 2.8 3.5 ± 0.7 0.0 ± 8.1 **T**2 Control group 5.5 ± 3.5 17.8 ± 3.9 7.8 ± 4.3 3.5 ± 0.8 3.0 ± 0.9 2.7 ± 0.8 3.7 ± 0.6 2.6 ± 0.8 13.4 ± 3.0 24.1 ± 5.5 29.4 ± 8.7 T1 2.4 ± 0.9 2.6 ± 0.9 2.5 ± 3.0 7.4±4.7 8.0±4.7 5.5 ± 4.7 6.7 ± 4.1 3.0 ± 1.0 3.7 ± 0.6 2.6 ± 0.8 31.0 ± 9.0 27.6±8.3 T4 31.3 ± 8.0 5.3 ± 4.6 2.4 ± 0.8 3.8 ± 0.6 6.2 ± 4.1 3.0 ± 0.9 2.5 ± 0.8 2.4 ± 0.8 13.1 ± 3.0 26.7±4.9 7.6 ± 4.0 17.9±4.2 T3 5.9 ± 3.9 2.8 ± 0.9 2.3 ± 0.8 27.3±4.5 2.3 ± 0.8 3.8 ± 0.5 3.6 ± 3.0 8.0 ± 3.8 8.1 ± 4.3 4.7 ± 4.1 2.3 ± 0.7 31.4 ± 8.1 Intervention group 27.3±5.0 6.2 ± 3.8 2.3 ± 0.8 17.7 ± 4.0 17.8 ± 4.3 4.8 ± 4.2 2.9 ± 0.9 2.4 ± 0.8 3.8 ± 0.6 2.3 ± 0.6 31.6 ± 7.9 13.2 ± 2.9 T1 RI – Perspective Taking^a RI – Empathic Concern^a Number of subjects CRA – Self-Esteem^c CRA - Disruption^c CRA - Finances^c CRA - Support^c JoR - Currente CRA - Health^c HADS-Ab HADS-D^b SSCOf

Index; QoR, Quality of Relationship; RQI, Relationship Quality Index; SSCQ, Short Sense of Competence Questionnaire. a Score range 0-28. b Score range 0-21. c Score range 1-5. d Score with dementia, and hours spent on care were added as covariates. The Akaike Information Criterion indices for model fit were: 3,171.021 and 2,345.346 for IRI - Perspective Taking Values are presented as mean ± SD unless indicated otherwise. CRA, Caregiver Reaction Assessment; HADS, Hospital Anxiety and Depression Scale; IRI, Interpersonal Reactivity range 7-42. eScore range 4-20. Score range 7-35. The intercept was modeled as a random effect, all the other effects were modeled as fixed effects. Age, cohabiting with the person and IRI – Empathic Concern, respectively.

 Fable 3. Differences between the groups on all outcome measures over time (linear mixed model analyses)



Dement Geriatr Cogn Disord Extra 2018;8:453–466					
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Table 4. RCIs for all outcome measures and both groups, T1–T2

	Intervention group		Control group		
	reliably changed reliably changed (negatively), n (positively), n		reliably changed (negatively), n	reliably changed (positively), n	
IRI – Perspective Taking	2 (of 141)	9 (of 141)	3 (of 51)	4 (of 51)	
IRI – Empathic Concern	7 (of 140)	5 (of 140)	1 (of 50)	2 (of 50)	
HADS-D	7 (of 130)	6 (of 130)	5 (of 50)	3 (of 50)	
HADS-A	5 (of 134)	5 (of 134)	1 (of 50)	4 (of 50)	
CRA – Disruption	4 (of 139)	5 (of 139)	3 (of 50)	2 (of 50)	
CRA – Health	5 (of 139)	5 (of 139)	3 (of 52)	4 (of 52)	
CRA – Support	7 (of 139)	2 (of 139)	1 (of 47)	4 (of 47)	
CRA – Self-Esteem	6 (of 137)	5 (of 137)	1 (of 52)	2 (of 52)	
CRA – Finances	12 (of 138)	16 (of 138)	6 (of 53)	6 (of 53)	
RQI	8 (of 125)	4 (of 125)	2 (of 49)	1 (of 49)	
QoR – Current	5 (of 110)	12 (of 110)	3 (of 44)	4 (of 44)	
SSCQ	5 (of 138)	3 (of 138)	2 (of 53)	3 (of 53)	

RCIs were based on a 90% confidence interval. All scores were recoded so that negative change indicates change for the worse, e.g., less empathy, more depression, more burden, and positive change indicates change for the better, e.g., less depression, more empathy, etc. CRA, Caregiver Reaction Assessment; HADS, Hospital Anxiety and Depression Scale; IRI, Interpersonal Reactivity Index; QoR, Quality of Relationship; RCI, Reliable Change Index; RQI, Relationship Quality Index; SSCQ, Short Sense of Competence Questionnaire.

Table 5. RCIs for all outcome measures and both groups, T1-T3

	Intervention group		Control group	
	reliably changed (negatively), n	reliably changed (positively), n	reliably changed (negatively), <i>n</i>	reliably changed (positively), n
IRI – Perspective Taking	4 (of 123)	2 (of 123)	0 (of 40)	2 (of 4)
IRI – Empathic Concern	4 (of 119)	6 (of 119)	1 (of 40)	2 (of 40)
HADS-D	10 (of 112)	2 (of 112)	1 (of 43)	4 (of 43)
HADS-A	4 (of 117)	3 (of 117)	2 (of 43)	2 (of 43)
CRA – Disruption	8 (of 121)	6 (of 121)	5 (of 42)	0 (of 42)
CRA – Health	8 (of 122)	4 (of 122)	4 (of 42)	2 (of 42)
CRA – Support	11 (of 120)	7 (of 120)	4 (of 39)	0 (of 39)
CRA – Self-Esteem	4 (of 120)	6 (of 120)	4 (of 41)	2 (of 41)
CRA – Finances	17 (of 120)	6 (of 120)	4 (of 43)	3 (of 43)
RQI	4 (of 107)	5 (of 107)	1 (of 38)	2 (of 38)
QoR - Current	4 (of 98)	4 (of 98)	3 (of 33)	1 (of 33)
SSCQ	4 (of 121)	2 (of 102)	3 (of 43)	1 (of 43)

RCIs were based on a 90% confidence interval. All scores were recoded so that negative change indicates change for the worse, e.g., less empathy, more depression, more burden, and positive change indicates change for the better, e.g., less depression, more empathy, etc. CRA, Caregiver Reaction Assessment; HADS, Hospital Anxiety and Depression Scale; IRI, Interpersonal Reactivity Index; QoR, Quality of Relationship; RCI, Reliable Change Index; RQI, Relationship Quality Index; SSCQ, Short Sense of Competence Questionnaire.

slowly, and that they had learned to let go of disagreements rather than starting or continuing arguments. This is also promising because it can lead to a more positive living situation for both the caregiver and the person with dementia.

We did not find significant change on the included questionnaires. The two previous intervention studies focused on increasing empathy (measured with the IRI) in dementia





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DOI: 10.1159/000494660 © 2018 The Author(s). Published by S. Karger AG, Basel www.karger.com/dee

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caregivers – the web-based skills training (STAR) [13] on both cognitive and affective empathy and TDL [14] on cognitive empathy – found significant increases at group level. However, these interventions are not directly comparable to ours: the intervention group of the STAR training consisted of both informal caregivers and volunteers in dementia care, had a small sample size (intervention group: n = 27; control group: n = 32), and used a web-based portal, consisting of skill-building modules as well as peer and expert groups for support and information exchange, and no simulation techniques to heighten empathy. The TDL (n = 35) did use simulation techniques (using virtual reality glasses) and an e-learning course, but did not include a control group. The change in cognitive empathy in that study could therefore be due to other factors (e.g., the passing of time) rather than to the intervention per se.

A systematic review [17] suggested that simulation may be an appropriate educational methodology for developing understanding, empathy, and/or empathic behaviors in health care students. However, there was a large variety in the effect sizes among the reviewed studies. The interventions showing larger effects included a range of educational features, such as role playing, and accompanying feedback. The Into D'mentia intervention did include a group session in which best practices were shared, but role playing and feedback were not included. Maybe if the Into D'mentia intervention were extended by including more educational aspects, changes on the questionnaires would emerge.

The absence of change on the questionnaires between the groups over time in our study could be due to a number of other issues. First, the intervention consisted of one short (20 min) simulation experience and one (half day) group meeting. Several caregivers noted during the interviews that they would have liked more group meetings or a booster session, including more support, and practical tips and tricks to help them in their caregiving tasks. Second, the simulation focuses on the beginning stage(s) of (primarily Alzheimer's) dementia. However, the majority of the caregivers in the intervention group had been a caregiver for more than a year, and several caregivers noted that the simulation was not applicable to their situation anymore because the dementia of their loved one had progressed and other dementia-associated problems had arisen. It is possible that changes on the questionnaires would emerge if the Into D'mentia intervention included more simulation and group sessions specifically designed for specific types of dementia (e.g., Alzheimer's dementia, vascular dementia) and the different stages (mild, moderate, severe) as the dementia progresses, more educational elements, and more specific tips and tricks that caregivers could use in their dayto-day care for their loved one with dementia. Third, in the Netherlands, there are a number of supportive services available for caregivers which are viewed as "usual care." As a consequence, the control participants in our study also had support, which may have resulted in a limited contrast between the two groups. However, it would have been unethical and unfeasible to deprive our participants of usual care.

On the other hand, the lack of change on the questionnaires could be due to methodological issues. First, due to practical issues, the participants were not randomized [18]. In order to overcome this, the groups were (successfully) group-matched on sex and level of education. However, the control group was slightly (but significantly) older than the intervention group, spent more hours on caregiving, and experienced more anxiety and burden than the intervention group. In addition, the control group was considerably smaller than the intervention group, leading to lower statistical power. This was due to difficulties in recruiting control participants; at the time the recruitment started, many caregivers in our recruitment region were already taking part in scientific studies including informal caregivers and were as such not eligible for (or willing to participate in) our control group. Also, there was a large dropout rate, leading to even smaller sample sizes at the last measurement. In addition, while the caregivers who dropped out and completed all measurements did not differ on most of the measured variables, they could be different in unobserved characteristics. Another





Dement Geriatr Cogn Disord Extra 2018;8:453–466		
DOI: 10.1159/000494660	© 2018 The Author(s). Published by S. Karger AG, Basel	

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possible explanation lies in the questionnaires used. To measure empathy, we used the IRI, arguably the most frequently used measure to assess empathy, especially in the general (not professional/medical) population. However, despite its wide usage, some of our caregivers found the questions difficult to answer, even after further clarification of specific questions that was given to them if asked for during the interviews. In addition, some researchers argue that the IRI measures trait empathy [33, 34] rather than state empathy, and in hindsight this questionnaire might not have been the best measure to assess change. Moreover, since (empathy) questionnaires rely on self-report, one could argue that only the appraisal of empathy was measured - the caregivers' opinion about how they would feel or act in a certain situation rather than the emotion or behavior itself. A means to overcome these questionnaire-related problems is to also include objective measures of empathy to complement the IRI. This way, it would also be possible to assess whether these measure the same construct or not. No objective empathy measures were used in this study because filling out the questionnaires already was time consuming for the participants and we were trying to keep the time investment to a minimum. The original idea of the current study was to also develop a prediction model for change [18]. However, due to the absence of change on the questionnaires, this idea was abandoned.

Despite these limitations, this study has direct relevance for both (clinical) practice and research. The intervention contributed to enhancing caregivers' understanding of (people with) dementia and helped them to feel more effective in caring for their loved one. If the clinician's goal is to heighten understanding and improve the caregivers' experience, this intervention is useful. Future research can consider enriching this intervention with other aspects such as educational material, more simulations, and (group) sessions, tailored to the individual caregiver and his/her situation, and examine whether these new interventions also yield change on questionnaires. These new, more personalized interventions designed for dementia caregivers could go a long way in helping caregivers to better understand the persons with dementia they care for. This could in turn not only assist the caregivers in their caregiving tasks, but also enhance their own well-being and that of the person with dementia they care for.

Acknowledgments

The authors thank the Department of Psychiatry, VU University Medical Center, Amsterdam Department of Psychiatry; De Wever Tilburg; IJsfontein, Amsterdam; Ideon, Amersfoort; and Stichting Into D'mentia for their help in developing the Into D'mentia simulator training. They would especially like to thank all the informal caregivers who participated in this study for their time and openness regarding their caregiving experiences.

Statement of Ethics

Caregivers' written informed consent was obtained.

Disclosure Statement

The authors have no conflict of interest to declare.





Dement Geriatr Cogn Disord Extra 2018;8:453–466		
DOI: 10.1159/000494660	© 2018 The Author(s). Published by S. Karger AG, Basel	
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Funding Sources

This work was supported by the program Memorabel of The Netherlands Organization for Health Research and Development (ZonMw), part of The Netherlands Organization for Scientific Research (NWO) and Alzheimer Nederland. However, solely the authors are responsible for the design and conduct of this study, all analyses, as well as the drafting and editing of this article.

Author Contributions

L.H. Jütten, R.E. Mark, and M.M. Sitskoorn contributed to study concept and design, participant and data acquisition, and data interpretation. L.H. Jütten executed the statistical analyses and wrote the first draft of the manuscript. The other authors provided critical feedback during the development of the manuscript and approved the final draft. All authors agree to be accountable for all aspects of the work and ensure that questions related to the accuracy or integrity of any part of the work were appropriately investigated and resolved.

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