



Cognitive Stimulation Therapy

Model-Based Cultural Adaptation and Manual Translation of an Evidence-Based Psychosocial Group Therapy for People With Dementia

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Abstract: Cognitive stimulation therapy (CST) is a manualized psychosocial group intervention for people with mild to moderate dementia. Because of its broad scientific evidence and cost effectiveness, CST is now used globally. To ensure replicability and quality standards of the intervention in other cultures, Aguirre et al. (2014) developed guidelines for cultural adaptation of CST based on the formative method for adapting psychotherapy (FMAP). Following this community-based approach, we adapted and translated the English CST manual into German, including multiprofessional focus groups, two adaptation cycles, and two pilot CST groups ($n = 13$) in different settings representative of the German healthcare system. Effectiveness in both groups was assessed by pre-post comparison of standard scales on cognition, depression, quality of life, and self-efficacy. We were able to replicate previous findings of improved cognition as measured by the ADAS-Cog, with effect sizes in the same range as in previous randomized controlled trials. Additionally, self-efficacy increased in post-test compared to the pre-test, indicating that CST might trigger cognition through positive, self-rewarding activation.

Keywords: dementia, psychosocial intervention, cognitive stimulation, self-efficacy

Introduction

Over the past decade, cognitive stimulation therapy (CST) has been increasingly adapted, evaluated, and implemented across Europe and worldwide. Originally derived based on a Cochrane systematic literature review of available psychosocial interventions (Spector et al., 2001), CST is based on Kitwood's (1993) patient-centered approach and incorporates a biopsychosocial model of dementia (Spector & Orrell, 2010).

According to a widely accepted definition of psychosocial interventions, CST is "engagement in a range of activities and discussions (usually in a group), aimed at general enhancement of cognitive and social function" (Clare & Woods, 2004). On the one hand, it differs from cognitive training, i.e., guided practice on a set of standard tasks in order to improve a specific cognitive function, and, on the other hand, from cognitive rehabilitation, a rather individualized approach aimed at improving performance in everyday life in order to achieve preselected personal goals. The main principles of CST applied in each session are *focusing on opinions rather than facts* by using new ideas, thoughts, and associations, *providing orientation* (date, group name,

name tags) to make the participants feel safe and self-confident, *stimulating cognition through multiple sensory activation*, and *using reminiscence as an aid to the here-and-now* (Spector & Orrell, 2010).

CST sessions involve topics that might be included in other psychosocial interventions as well; the crucial point lies in the maximally stimulating way in which they are presented. In a large multicenter RCT involving 201 participants with dementia, Spector et al. (2003) demonstrated the efficacy of the 14-session Basic CST program delivered twice a week for groups of 5–7 participants. At follow-up, the intervention group had improved significantly compared to the control group in cognition and quality of life. After this initial trial, Maintenance CST was developed, comprising 24 weekly sessions aimed to maintain the achieved gains. In a second multicenter RCT, Orrell et al. (2014) demonstrated the effectiveness of Maintenance CST for self-rated and proxy-rated quality of life as well for cognition when combined with acetylcholine esterase inhibitor (ACHEI) medication. The same trial replicated the beneficial effects of Basic CST (Aguirre et al., 2013). Cost effectiveness studies showed that the costs and benefits of basic CST were in the same range as pharmacological interventions

(Knapp et al., 2006). Regarding the combination of Maintenance CST with ACHEI in mild-to-moderate dementia, when cognition was measured as outcome cost-effectiveness gains emerged (D'Amico et al., 2015). In summary, both Basic CST and Maintenance CST were shown to be effective in supporting cognition, both in combination with antedementia medication and for patients who prefer not to take ACHEI because of unwarranted side effects or interactions with other drugs in multimorbid health conditions.

Based on this evidence, in the UK CST was first recommended in 2006 by the NICE SCIE Guidelines and upgraded in the recent revision (NICE-SCIE Guidelines 2018; Recommendation 1.4.2): "Offer group cognitive stimulation therapy to people living with mild to moderate dementia." In these recently updated guidelines, CST remains the only manualized psychosocial intervention recommended to promote cognition, independence, and well-being for people with dementia.

CST has been translated and adapted to different cultures, including Japan (Yamanaka et al., 2013), Hong Kong (Wong et al. 2017), Brazil (Bertrand et al., 2018), and Sub-Saharan Africa (Mkenda et al., 2018). In Europe, the manual has been adapted in Italy (Capotosto et al. 2017), and in Denmark adaptation is ongoing. Thus, beyond the UK there is now broad evidence from several large RCTs confirming the efficacy of CST in delaying cognitive decline (Lobbia et al., 2018). Besides cognition, positive effects have been reported for quality of life, depressive symptoms, perceived social and emotional loneliness, and communication skills (McDermott et al., 2019).

The translation and cultural adaptation of a psychosocial intervention is a highly complex endeavor, as it is not self-evident that an intervention with proven efficacy in one culture has the same effect in another. Cultural adaptation involves a systematic modification of the treatment to consider language, culture, and context in a way that is compatible to the participants' cultural patterns, meanings, and values (Hwang, 2009). Thus, frameworks for adaptation of interventions that focus on people living with dementia first need to reflect on how dementia is perceived in the culture in which the intervention is to be used. Even in societies that might appear highly similar, the values, customs, educational, and healthcare systems may vary, which may influence the delivery and efficacy of the intervention not only on the part of the persons with dementia, but also on the part of the healthcare professionals (Voigt-Radloff et al., 2011).

The majority of frameworks previously used to adapt therapies to different cultures employed a theory-based, top-down approach (cf. Hwang, 2009), either by assuming equivalence of efficacy and thus just translating the manual to another language; or by delineating the mean lines of

adaptation in advance and piloting the modified manual in one cycle. Taking a community-based, bottom-up approach instead, Hwang (2009) proposed the formative method for adapting psychotherapy (FMAP), which involves collaborating with service users as a first step to generate and support ideas for therapy adaptation. Based on this approach, Aguirre et al. (2014) developed the "Guidelines for Adaptation of Cognitive Stimulation Therapy," to ensure the ecological validity of CST adaptations and adherence to the basic principles of CST in other cultures as well as to maximize its effectiveness and impact worldwide. The FMAP approach consists of five phases that target developing, testing, and reformulating therapy modifications. The phases involve (1) generating knowledge and collaborating with stakeholders, (2) integrating generated information with theory and empirical and clinical knowledge, (3) reviewing the initial culturally adapted clinical intervention with stakeholders and revising the culturally adapted intervention, (4) testing the culturally adapted intervention, and (5) finalizing the culturally adapted intervention (Aguirre et al., 2014).

In the present paper, we report the adaptation and translation of the English CST manual into German in accordance with the FMAP model. The bottom-up adaptation process included multiprofessional focus groups, two adaptation cycles, and a pilot study involving two CST groups in different care settings.

Methods

The process of cultural adaptation of the English CST manual took place in Berlin, Germany, and was guided by two trained CST facilitators. It was initiated on the publication of the German National Guidelines for Dementia (DGPPN & DGN, 2016), in which CST was recommended as an evidence-based, psychosocial intervention to delay cognitive decline. However, no culturally adapted manuals on basic and maintenance CST were available in German at the time.

Our project lasted a total of 24 months (see Table 1), counted from the first stakeholder interviews in August 2016 to the publication of the German Manual in July 2018 (Aguirre et al., 2018).

Pilot Study as Part of FMAP Stage 2

Participants for the two pilot CST groups were recruited in an outpatient neuropsychology practice and in a nursing home by flyers describing the CST program and the pre-post diagnostic procedure. Inclusion criteria from previous CST research guided the study and included participants if they

Table 1. Timeline of the project with FMAP stages and main actions for each phase

Stages/months	Main actions
FMAP 1 Months 0–3	Preparation/stakeholder contactors International workshop, Interview with stakeholders Focus Group 1: Multiprofessional Team with 2 neuropsychologists, 2 psychologists, 1 occupational therapist, 1 social worker
FMAP 2 Months 3–9	First test of adapted intervention (cf. Figure 1: cycle A) Pilot Study with 2 CST groups in inpatient and outpatient setting Pre- and post-tests ($N = 13$)
FMAP 3 Months 10–12	Review of adapted intervention Presentation and discussion on workshop at national meeting Focus Group 2: 6 CST group facilitators Integration of documentation of single sessions, participants' evaluations
FMAP 4 Months 13–21	Second test of adapted intervention (cf. Figure 1: cycle B) CST group in memory clinic setting Basic and maintenance CST, 3 course facilitators not involved in FMAP 2
FMAP 5 Months 21–24	Finalizing the manual Back translation of German version to English Revision of back-translated manual by manual authors

had mild-to-moderate dementia (diagnosed according to the DSM-IV; American Psychiatric Association, 2000), were able to engage in group activity for up to 1 hour, were able to understand verbal instructions and communicate verbally, and had no agitation or psychosis. We obtained informed consent from all participants or (in two cases) from their legal guardian prior to inclusion in the pilot study. The Ethics Committee at the Department of Psychology, Humboldt Universität Berlin (Reg.-No. 2016-21) approved the study. The group facilitators documented each session, and an independent observer did the pre-post assessment before and after the 14-session basic course.

Outcome measures were the Alzheimer's Disease Assessment Scale – Cognitive subscale (ADAS-Cog; Rosen et al. 1984) and the Mini Mental Status Examination (MMSE; Folstein et al., 1975) for cognition, and the QoL-AD (Logsdon et al., 2002) for quality of life. These well-established measures had been used in previous clinical trials (Orrell et al., 2014; Spector et al., 2003). We also used two self-report scales: To assess depressive symptoms, we used the Center of Epidemiological Studies – Depression scale (CES-D; Radloff, 1977), a 20-item measure developed for the assessment of depressive symptoms, asking how often participants had experienced symptoms such as negative mood, restless sleep, poor appetite, and feeling lonely over the past week. The CES-D is a measure of depressive symptoms in the community and was used here to characterize the sample and to examine possible beneficial effects of CST as a regular positive social activity.

We employed the General Self-Efficacy scale (GSES; Schwarzer & Jerusalem, 1995) as a measure of positive aspects of CST on coping, with scores ranging from 10 to

40, where 40 represents the maximum level of self-efficacy. Participants rated items (e.g., “I can manage to solve difficult problems if I try hard enough.”) on a 4-point scale ranging from 1 (*not at all true*) to 4 (*exactly true*). Table 2 displays the demographic and clinical characteristics of the two subgroups and the entire sample. We found significant differences between the two subgroups in age but not in any outcome measure. Therefore, the data of both subgroups were collapsed for the pre-post comparison.

Participants in both settings joined the basic CST group twice a week for 7 weeks. The groups were led by a trained CST facilitator (the first and second author of this paper) and a cofacilitator working in the respective setting. We applied Maintenance CST weekly over 24 weeks. Pre- and postmeasurements were conducted by trained independent observers, who were neither group facilitators nor worked in the respective setting.

Results

FMAP 1: Generating Knowledge and Collaborating With Stakeholders

As an initial stakeholder meeting, a workshop on ‘International Adaptation and Implementation’ discussed the planned cultural adaptation into German at the International CST Conference. Participants ($n = 10$) were psychologists and occupational therapists from Germany, the UK, The Netherlands, and Denmark. The discussed topics were (1) the dementia-related healthcare system in Germany and

Table 2. Demographic and clinical characteristics of both groups and test of baseline differences

	Outpatients (n = 6)		Residential home patient (n = 7)		All (N = 13)	
	M	SD	M	SD	M	SD
Age**	66.8	7.9	86.3	10.0	78.8	12.7
Sex (females)	3	-	4	-	7	-
Baseline measures					<i>t</i> (df)	<i>p</i>
ADAS-Cog	20.83	8.18	23.00	8.39	-.47 (11)	.65
MMSE	22.00	5.62	21.86	5.05	.48 (11)	.96
QoL-AD	31.83	2.99	34.43	8.10	-.74 (11)	.48
GSES	24.67	5.39	29.43	6.13	-1.47 (11)	.17
CES-D	13.00	9.67	10.86	8.67	.42 (11)	.68

Note. **Significant age difference ($p < .01$), all other measures did not differ ($ps > .1$). Abbreviations: ADAS-Cog = Alzheimer's Disease Assessment Scale; MMSE = Mini Mental State Examination; QoL-AD = Quality of Life - Alzheimer's Disease; CES-D = Center of Epidemiological Studies - Depression Scale; GSES = General Self-Efficacy Scale.

(2) the education of health professionals in Germany and how these general conditions affect delivery and distribution of CST. From an international perspective, in Germany the academization of nonmedical health professionals is less developed than in other Western European countries. Nonacademic health professionals in clinics or outpatient settings are not reimbursed for preparatory or conceptual work, such as developing and collecting materials for CST sessions. Easy handling of the manual and a collection of prepared materials was therefore considered necessary for high acceptance and dissemination of CST groups in Germany (cf. Aguirre & Werheid, 2018).

As further stakeholders, two patient-caregiver dyads, a general practitioner specializing in geriatrics, a psychologist, and a neurologist-psychiatrist were interviewed by the project leader (KW) regarding their views on optimal settings and organization of CST groups. Results from the content analysis of these interviews showed that, for participants with mild dementia living in the community, an outpatient practice would be the first option for a pilot study, as many potential participants were used to using this type of service. A second option would be a nursing home, though patients in this setting would likely be cognitively more impaired than those living in the community. As a third option, it was recommended to tie CST groups to a memory clinic, where CST could be recommended to newly diagnosed patients or outpatients with regular visits. As a fourth option, with the highest potential for community-based, low-threshold dementia care, it was recommended to organize and advertise CST groups in local district centers or district cultural centers. CST groups could be run in any room of the appropriate size with sanitary facilities and heating in winter, preferably with a pantry and barrier-free access.

Parallel to these activities, the two English manuals "Making a Difference" (Vol. 1 and Vol. 2; Aguirre et al., 2018; Spector et al., 2006) were translated to German,

containing descriptions of each session and an introduction to the general principles of CST.

Focus Group 1 was then organized with six dementia professionals discussing the first translated version of the manual. The participants were a social worker (1), an occupational therapist (1), a speech therapist (1), a psychology student (1), and two psychologists (2), all of whom fluent in English. To prepare the focus group, they received a copy of the original untranslated version and three published papers on the CST principles, efficacy, and implementation research. They were asked to describe (1) their impressions of CST in general, (2) whether the CST sessions named individually would work in their own work settings, and (3) how best to modify CST for their community. Apart from exchanging ideas, the goal was to build a sense of community, and strengthen referral networks.

FMAP2: Integrating Generated Information With Theory, Empirical and Clinical Knowledge

In the next step, we generated a first version of the German manual for the pilot Phase A in two parallel groups in settings one and two. For each session, we described two alternative options A and B, to assure that the cognitive demands could be optimally tied to the groups' capacities. Option A was for groups with fewer cognitive deficits living in the community, option B for more impaired groups, for example, in inpatient settings. Following the stakeholders' recommendation, the two options were described in detail and equipped with materials readily available on the internet and in a paper format, in order to minimize preparatory work for group leaders.

We conducted the pilot study as part of FMAP stage 2 as described above. After the 14-session basic CST program, the participants of the two groups (6 outpatient practice,

Table 3. Results of the pilot study (FMAP 2): Mean and standard deviations results of one-way ANOVAs, and effect sizes for all outcome measures before and after the 14-session CST Basic program for the entire group

	Pre (N = 13)		Post (N = 13)		F (df)	p	η^2
	M	SD	M	SD			
ADAS-Cog	22.00	8.02	19.15	7.71	5.97 (12)	.031*	.33
MMSE	21.92	5.09	23.23	3.09	2.57 (12)	.133	.18
QOL-AD	33.23	6.19	35.00	6.07	0.97 (12)	.345	.08
GSES	27.23	6.08	31.15	6.46	5.84 (12)	.032*	.33
CES-D	11.85	8.82	12.00	10.75	0.01 (12)	.940	.00

Note. * $p \leq .05$. η^2 = effect sizes Eta squared; ADAS-Cog = Alzheimer's Disease Assessment Scale; MMSE = Mini Mental State Examination; QOL-AD = Quality of Life – Alzheimer's Disease; GSES = General Self-Efficacy Scale; CES-D = Center of Epidemiological Studies –Depression Scale. Note that lower ADAS-Cog scores signify increased test performance.

7 nursing home) showed significantly lower scores in the ADAS-Cog than before, which signifies an improvement. Scores in the GSES were significantly higher after the basic CST program.

Twelve of the 13 patients agreed to participate in the 24-session Maintenance program, which started after a 2-month summer break. One male participant in the outpatient group stopped participation because he preferred individual cognitive therapy. A follow-up with the above-described outcome measures was conducted after finishing the Maintenance program 6 months later. At this point in time, 4 of the remaining 12 participants had dropped out, 1 in the outpatient practice had died of stroke, and 3 had changed their place of residence. For the remaining 8 patients (4 outpatients, 4 residential home patients), the ADAS-Cog was $M = 23.5$ ($SD = 11.0$), MMST $M = 17.5$ ($SD = 6.2$), QoL-AD $M = 40.0$ ($SD = 3.7$), and GSES $M = 28.9$ ($SD = 15.7$). None of the outcome measures changed significantly (all $ps > .05$). Participants who dropped out did not differ from the remaining sample in any baseline measure (all $ps > .1$).

An additional post-hoc analysis was conducted, calculating reliable change indices (RCI; Jacobson & Truax, 1991) for each patient's ADAS-Cog scores before and after Maintenance CST. RCIs were obtained by dividing individual post minus pre differences of means by the standard deviation of this difference. Inspection of these individual RCIs revealed that after Maintenance CST 6 out of 8 patients were stable on the ADAS-Cog, one improved, and one declined (Table 3).

FMAP 3: Review of the Culturally Adapted CST Intervention and Further Revision

An independent observer interviewed participants of the CST groups after each session and asked whether they liked the group, what they liked most, and what they disliked. Also, the four CST facilitators leading the two CST groups in the outpatient and inpatient setting were invited to partic-

ipate in Focus Meeting 2. Table 4 summarizes the main suggestions emerging from the patient interviews and Focus Group 2.

FMAP 4: Second Test of Adapted Intervention

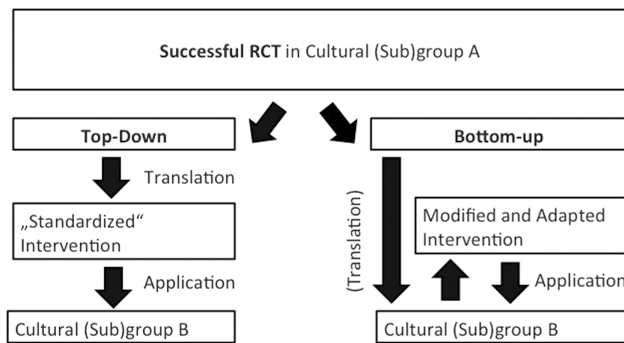
As Figure 1 indicates, the revised manual including the newly developed materials were tested again (cf. Figure 1 “cycle B”) in a memory clinic, a typical setting in Germany besides outpatient practices or nursing homes. We could not conduct extensive pre-post testing and interviews after each session in this setting for economic reasons, but an independent observer did interview participants after finishing the group on how they liked it, what they liked most and what they disliked most about it. Every 4 weeks, a certified CST trainer and member of the study team supervised the facilitators. These feedback sources led to several minor changes being made, such as adding suggestions for materials in the household and words sessions. Also, the schedule of the sessions was changed with the song featuring before the welcome and orientation parts because the pilot groups (both facilitators and participants) had shown a preference toward a singing start, probably following a cultural custom they were used to in church or in previous groups or gatherings. Also, the facilitators reported that starting with a song was extremely stimulating and increased motivation as well as cognitively activating the participants for the following orientation part of the session.

FMAP 5: Finalizing the Culturally Adapted Intervention: Back Translation and Final Revision

The finalized manual included the last revisions emerging from FMAP phase 4 in the description as well as feedback from participants and facilitators to the introductory chapters describing the general CST principles in the

Table 4. Revision of adapted and piloted CST version in FMAP stage 4. Main changes based on participant interviews (left) and Focus Group 2 (right)

Suggestions of participants	Suggestions of Focus Group 2
Session titles: Name only topics, e.g., “words,” “numbers,” etc., not direct translation “Spiele,” which is in German the same word for “game” and “children’s play”	Manual title: Use direct translation “Kognitive Stimulation” instead of “Kognitive Anregung,” for better recognisability and correspondence with literature and guidelines
Materials: Consider East-West differences in famous people, films, and places	Materials: Use turntable for facilitating choices, e.g., for “thinking cards”
Competitions: Use only team scores, to avoid situations in which participants might feel ashamed, since this brings up aversive childhood experiences in authoritarian learning situations and counteracts cognitive stimulation.	User friendliness of manual: Provide for each session two variants A and B in each session; integration of basic and maintenance CST should be visualized by a crosswalk table, provide materials on the web, Annex with easily copied format of materials.

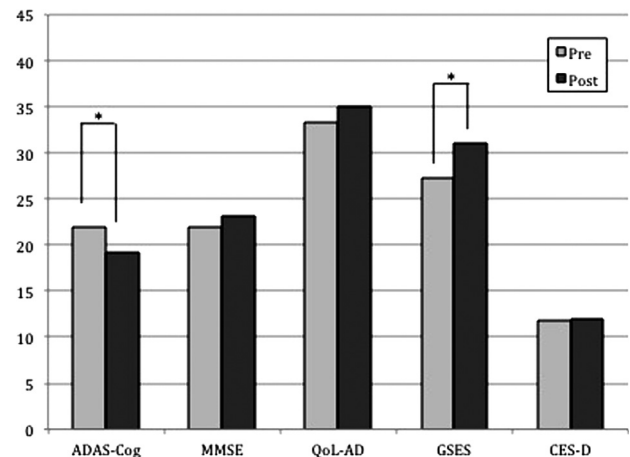
**Figure 1.** Cultural adaptation of psychosocial interventions: Comparison of top-down theory-based approach and bottom-up community-based approach according to Hwang (2009).

German version. Next, the final version was backtranslated to English by a native English-speaking psychologist not belonging to the study group. This version was sent to the authors of the English original, who revised the backtranslation; the German team their questions and comments and used them for further revisions (Figure 2).

Discussion

The current study was a model-based adaptation and translation of the English CST manual into German. The tools used in the bottom-up adaptation process were multiprofessional focus groups, two adaptation cycles, and a pilot study involving two CST groups in different care settings. Additionally, the manual was backtranslated into the original language.

The pilot study was clearly limited by the small sample size. Further, the pre-post design of the pilot study, without a control group, does not meet the standard requirements of a clinical study. In the international context, there are several large high-quality RCTs (D’Ambrosio et al., 2017), but many research questions regarding the specific mechanisms of action, or particular aspects of CST groups that lead to cognitive improvement, remains unresolved and should be addressed by future research. The finding of an

**Figure 2.** Results of the pilot study, pre-post assessment before and after the CST basic course (both groups, $N = 13$).

effect size in the middle range for the ADAS-Cog was nevertheless an encouraging finding and fully in accordance with previous clinical studies (e.g., Orrell et al., 2014; Spector et al., 2003).

Though it confirms previous research, one should interpret the finding of a stabilizing effect of Maintenance CST on cognition with caution, because the sample size was even smaller here. However, the additional post-hoc analyses documenting stable cognition over 8 months may be taken as a promising starting point for future long-term analyses. Given the expected decline of cognition in dementia, stable cognition can be considered a desired outcome. This finding should be revisited in a larger control-group design.

A further finding of this small-scaled pilot study was that self-reported self-efficacy, as measured by the GSES, increased after 14 sessions of basic CST. In light of the above-mentioned small sample sizes, however, this finding should not be overestimated. Nevertheless, it may indicate that the General Self-Efficacy Scale, included in our pilot study as a measure to examine positive aspects of CST on coping with chronic, degenerative disease, is a sensitive outcome measure in this context. Interestingly, although

self-efficacy has shown to be closely related to depressive symptoms in other age-related, chronic disease conditions (Volz et al., 2019), this change was not flanked by a change in depressive symptoms. Factors other than decreasing depression, possible a gain in executive functioning (cf. Hall et al., 2013), might have contributed to the findings. Further investigation on these interconnections would be a valuable topic for future research on the mechanisms of action of CST.

In conclusion, the German adaptation and translation of the CST program appears to have produced a manual applicable in variable settings. On an international level, the availability of an approved standardized manual is now on the same level as the Japanese, Spanish, Italian, Portuguese, Dutch, and Swahili versions. Two aspects warrant further evaluation: the implementation in the German healthcare system and further research on the effectiveness of CST in Germany. This small-scale adaptation study may serve as an example for the culture-sensitive transfer of psychosocial interventions and for the use of standardized measures to assess how such interventions may facilitate the growth of competences alongside the slowing of cognitive impairments.

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Received October 17, 2019

Accepted June 29, 2020

Published online October 30, 2020

Acknowledgments

Many thanks to our colleagues and cofacilitators Sabine Heel, Zentrum für Ambulante Neuropsychologie und Verhaltenstherapie (ZANV) Berlin, and Anja-Ina Hindenburg, Pflegewohnheim Am Kreuzberg. Amy Streater, Martin Orrell, Bob Woods, Belinda Dixon, and four anonymous persons (two patients, a geriatrician, and a psychiatrist) provided valuable advice during the adaptation process. We are very grateful to Sandra Dick, Christian Kloß, Antje Kraft, Andrea Lohse, Christina Pfaff, Denise Schmid, Matthias Volz, Anne-Mette Wegner, Jan-Dirk Werner, and Katja Wurtz for participating in the focus groups and for assisting in piloting earlier versions of the manual.

Conflict of Interest

The authors declare no conflict of interest.

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