Impact of a Mental Health Gap (mhGAP) Module on Behavioral and Psychological Symptoms of Dementia (BPSD) and Caregiver Burden in a South Indian Community

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Abstract

Background: Non pharmacological interventions are the first line treatment recommended for behavioral and psychological symptoms of dementia and mental health gap module is a non-pharmacological interventions based program developed by Word Health Organization for dementia patients especially in low and middle income countries. This study was conducted to evaluate the impact of mental health gap module on Behavioral and psychological symptoms of dementia and caregiver burden in a south Indian rural community.

Methods: A quasi experimental one group pretest posttest time series design study was conducted among 61 elderly with dementia in a south Indian rural community who were selected using purposive sampling. Pre interventional assessment was done with Neuropsychiatric Inventory Questionnaire and Zarit Burden Interview. A multifaceted mental health gap intervention was delivered to the patients through monthly home visit by community health workers for one year and impact on behavioral and psychological symptoms and caregiver burden was tested at six weeks, three months and 12 months.

Conclusion : There was a significant improvement in behavioral and psychological symptoms of dementia and caregiver burden during study period. This study proved that behavioral and psychological symptoms of dementia and caregiver burden can be managed though home based non pharmacological interventions using community health workers which is a beneficial and cost effective model for low and middle income countries.

Key words: *Behavioral psychological symptoms of dementia (BPSD), caregiver burden, mhGAP module, South India, Rural community*

Introduction

Dementia is a disease in old age marked by progressive cognitive impairment and by 2050 about 132 million people in the world will have dementia[1]. There were 3.7 million elderly in India with dementia in 2010 and will rise to 7.6 million by 2030[2]. South Indian states have the highest proportion of elderly with Kerala at the peak of 12.6%[3]. These states will be going to face a significant rise in dementia cases in the near future.

Behavioral and psychological symptoms of dementia (BPSD) are a group of non-cognitive, distressing symptoms found in 90% of patients with dementia and associated with a poorer prognosis, rapid cognitive decline, increased institutionalization, increased health care costs and loss of quality of life[4,5]. Caregiver burden

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is another phenomenon which threatens the physical, psychological, emotional and functional health and increases morbidity and mortality of the caregiver[6]. Majority of dementia caregivers reports high levels of stress, depression and anxiety[7].

Antipsychotics prescribed for BPSD has serious adverse effects, [8] thus non pharmacological methods (NPIs) are advised by various clinical guidelines[9]. World Health Organization (WHO) developed Mental Health Gap (mhGAP) intervention guide[10] to deal with the mental health gap occurred due to the unavailability of services in rural areas in low and middle income countries. In India, mhGAP is more than 90%[11], so community health workers (CHWs) can be utilized to manage community dwelling patients. The mhGAP guide has to be adapted to local situations depending on the contextual differences in prevalence and availability of resources and would be helpful for developing countries where the scarcity of the specialists is high in rural areas. Though some studies were conducted in many middle or low income countries[12], not many Indian studies were found regarding the effectiveness of mhGAP module on community dwelling dementia patients.

Materials and Methods

This study was conducted to evaluate the impact of modified mhGAP module on BPSD and caregiver burden. A quasi experimental one group pretest posttest time series study was conducted among elderly above 60 years of age who were living in Thalikkulam Panchayath at Thrissur district of middle Kerala. Seventy one patients living with a primary caregiver for a minimum period of one year were selected using purposive sampling after screening with Brief Community Screening Instrument for Dementia (CSID-BRIEF). Patients with vascular dementia and with severe medical or psychiatric illness were excluded. The study was conducted in three phases.

First phase (pre intervention):

Tool 1: A validated and pre-tested socio personal variables questionnaire with 16 items for patients and caregivers.

Tool 2: Neuropsychiatric Inventory Questionnaire (NPI-Q) is a standardized informant-based instrument measuring both the severity and distress of 12 BPSDs. The severity scale scores from 1 to 3 (mild, moderate and severe) and distress scale scores from 0 to 5 (no distress; minimal distress; mild distress; moderate distress; severe distress and extreme distress). Tool was validated by subject experts and reliability was established by inter rater method.

Tool 3: Zarit Burden Interview (ZBI) is a 22 item standardized tool to measure subjective burden of caregivers with item score ranges from 0 to 4 (never, rarely, sometimes, quite frequently and nearly always). Total score ranges from 0 to 88 and are categorized to no burden (0-20), mild to moderate burden (21-40), moderate to severe burden (41-60) and severe burden (61-88). Tool was validated by subject experts and reliability was established by test retest method.

Second phase (intervention)

The original mhGAP module 2.0 with seven sections was translated to Malayalam and modified according to cultural affiliations, from additional literature review from dementia care guides and palliative care modules and contributions from three focus group discussions with five CHWs. Evaluation and validity was done by independent experts from geriatric psychiatry, geriatric psychiatric nursing, community medicine, and community health nursing. Conceptual adequacy, appropriateness and presentation style was revised before finalizing. The flow and ease of understanding and simplicity of the language was validated by language experts. Pilot study was done with ten patients from the target population, following which vocabulary indicating the difficult terms and appropriateness of illustrations was reviewed.

We have selected seven CHWs and a multifaceted intervention was conducted as shown in table 1. We divided the 71 patients among CHWs and the interventions were delivered through monthly home visits. Each CHW kept a field diary and they recorded the interventions given and improvements noticed on each visit. Follow up meetings were conducted by researcher with CHWs every month and necessary guidance were given. Reinstitution of intervention was given after six months.

Third phase: (post intervention)

Evaluation of the effect of mhGAP module was carried out through home visits by researcher after six weeks, three months and 12 months. The impact was assessed by change in NPI-Q and ZBI scores. Ten patients dropped out during the study period and final sample size was 61.

Data Analysis

Data were tabulated and analyzed using EpiInfo 7.0 software. The test of normality (Kolmogorov–Smirnov test) was applied and data was found to be non-normally distributed (P <0.05), hence median and interquartile range were used to describe the data. Friedman's test was used to find the association between pre and post-test scores and Wilcoxon signed rank test was used to ascertain the differences between pre and post-test changes.

Results

Sociopersonal variables: Most (75%) of the patients were females with a mean age of 80.03+7.67 years and 64.8% were educated up to primary school. Majority (70.4%) were widows and 69% were living in a three generation family and 77.5% were living in their own house. Mean duration of dementia was 38.04 months.

The mean age of the caregivers was 50.38+13.21 years and most were females (98.6%), married (84.6%) and educated up to primary school (36.6%). Most were daughter- in- laws (66.2%) and 39.4% of patients were partially dependent for day to day functioning. Mean duration of caregiving was 38 months and 70.4% of the caregivers did not have any assistance in care giving.

BPSD and caregiver burden: When analyzed the pretest data, delusion (77%), apathy (75.4%) and agitation (72.1%) were the most common and hallucination (32.8%) and euphoria (26.2%) were the least common BPSD seen. When assessed for BPSD distress, apathy (74.6%), delusion (70.4%) irritability (69%) and agitation (69%) were the most common and hallucination (31%) and euphoria (25.4%) were the least common distress producing symptoms found. Regarding burden, 40.8% of the caregivers experienced mild to moderate burden and 38% of them were having moderate to severe burden (Fig 1).

Effect of mhGAP on BPSD and caregiver burden: After the mhGAP intervention, there was a significant difference in all BPSD severities (Fig 2) except for motor disturbances, all BPSD distress (Fig 3) and caregiver burden after 12 months (p<0.05). (Table 2,3). Post hoc analysis revealed that most of the significant changes in BPSD and burden happened during longer periods pretest to 12 months and 6 weeks to 12 months.

Table 1: Interactive session on mhGAP module interventions

Section	Content	Teaching learning techniques	Duration
Introduction	Dementia, Definition of dementia, Types of dementia, Stages of dementia	PowerPoint Presentation	5 mins
Creating awareness	Introduce the concept to family Revealing diagnosis of dementia Explain the treatment plan of dementia	PowerPoint Presentation	2 mins
Managing behavioral and psychological problems	Types of BPSD, Causes of BPSD Strategies to manage BPSD	Think-pair-share (scenically represented question was asked, participant was allowed to think alone and then discuss with neighbour before settling on a final answer)	5 mins

Improving social life and daily routine	How to schedule daily routine, Promoting independence, Exercises , Falls prevention, structural modifications at home	Vignette (a patient scenario was given) and discussing possible interventions	3 mins
Improving intellectual abilities	Reorientation techniques, Communication techniques	Group discussion	3 mins
Physical and mental abuse	Identifying signs of abuse, Reporting abuse	Lecturing with PowerPoint Presentation	1 min
Managing caregiver burden	Identifying signs of burden, Structuring caregiving schedule, Training caregivers, Counselling caregivers, Social support and self-help groups	Role playing using participants on specific situations.	5 mins
Instructions to be given directly to caregivers	Safety at home, Wandering, Incontinence, Diet modifications, Personal hygiene, dressing, Insomnia, Infections, Constipation, Visual impairments, Palliative care	Brain storming	6 mins
Summary/Conclusion	Summarizing, clarifying doubts, follow up instructions	Distribution of leaflets/pamphlets	

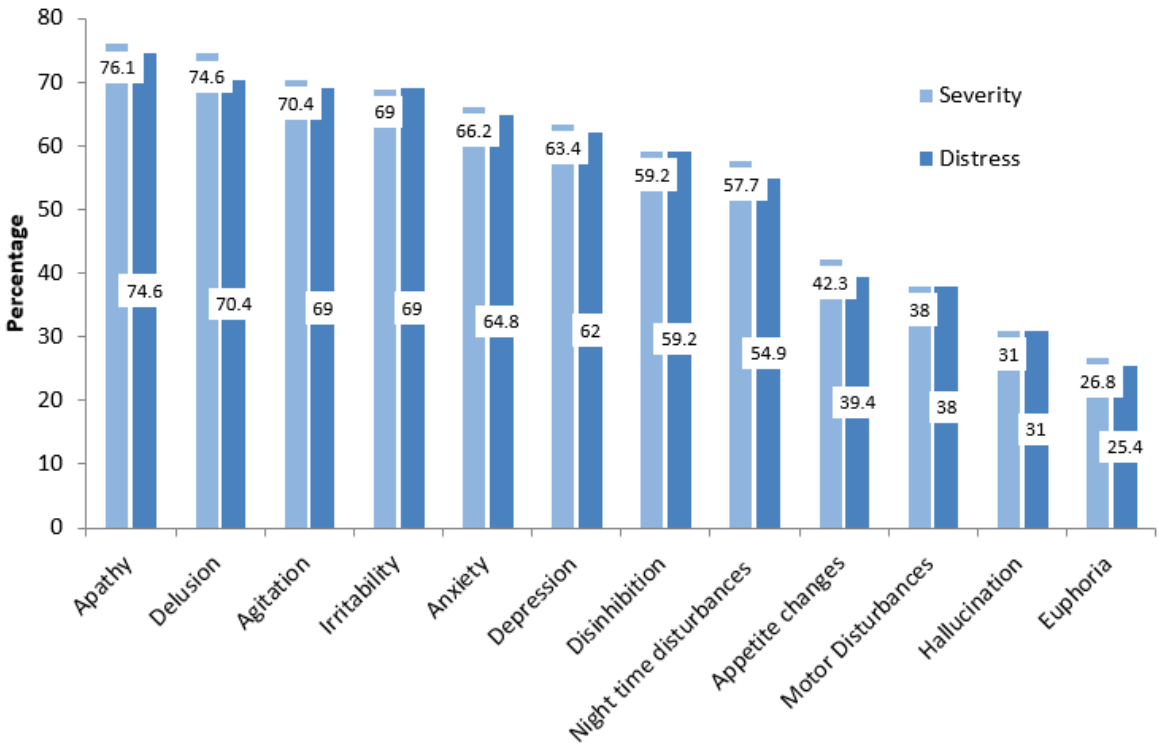

Fig 1: BPSD severity and distress among patients with dementia

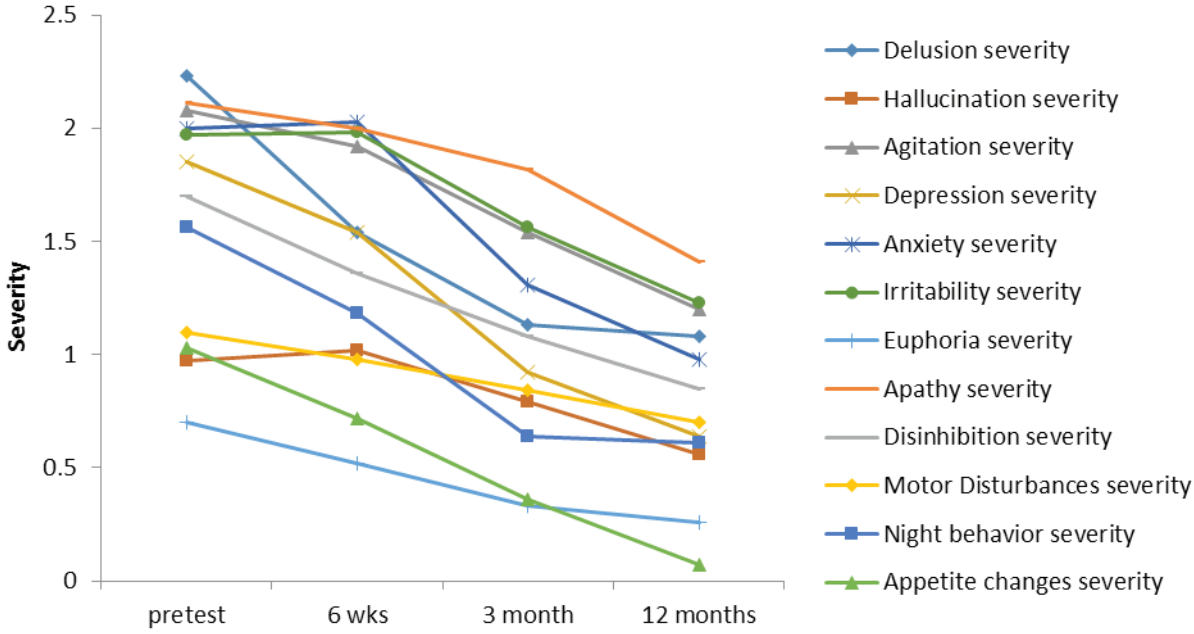

Fig 2: Change in BPSD severity over the study period n=61

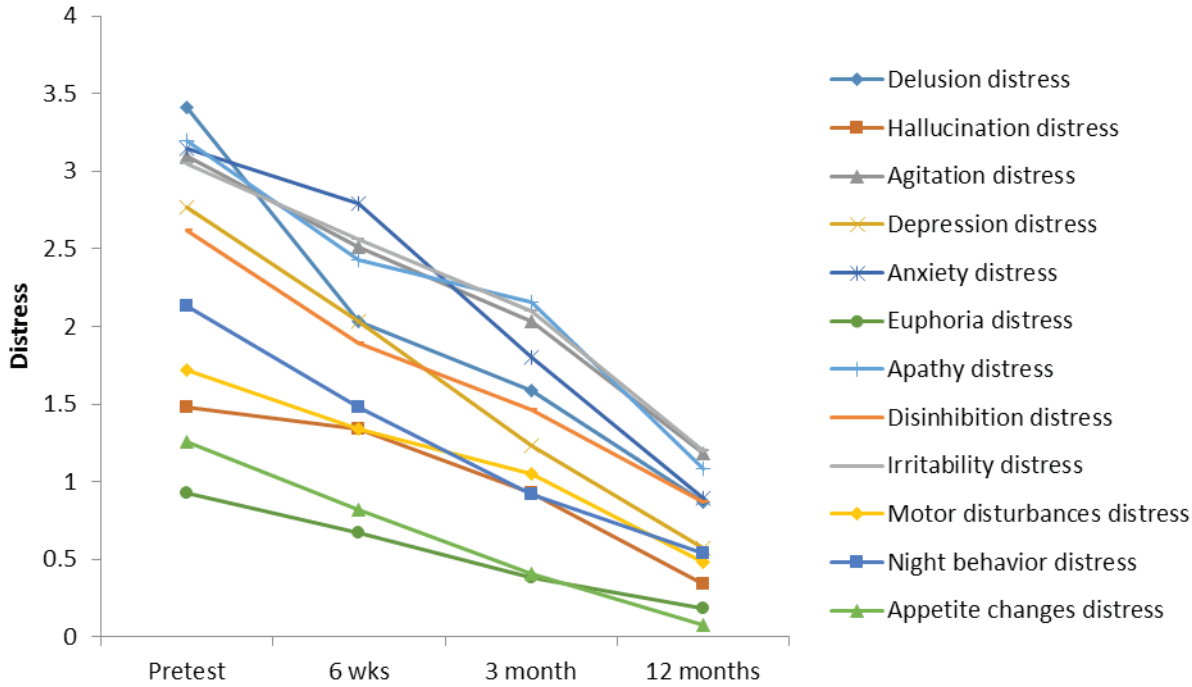

Fig 3: Change in BPSD distress over the study period n=61

Table 2: Comparison of BPSD severity scores before and after the implementation of mhGAP module

Variables	Pre test Median (IQR)	6 weeks Median (IQR)	3 months Median (IQR)	12 months Median (IQR)	χ2#	p value
BPSD total	19 (14.5 to 24)	16 (10.5 to 22)	10 (6 to 17)	8 (5 to 15)	75.18*	<0.0001
Delusion severity	3 (2 to 3)	2 (0 to 3)	1 (0 to 2)	1 (0 to 2)	42.84*	< 0.0001
Hallucination severity	0 (0 to 3)	0 (0 to 3)	0 (0 to 2)	0 (0 to 1)	9.06*	0.03
Agitation severity	3 (0 to 3)	3 (0 to 3)	2 (0 to 2.5)	1 (0 to 2)	29.48*	< 0.0001
Depression severity	3 (0 to 3)	2 (0 to 3)	0 (0 to 2)	0 (0 to 1)	39.08*	< 0.0001
Anxiety severity	3 (0 to 3)	3 (0 to 3)	2 (0 to 2)	1 (0 to 2)	46.18*	< 0.0001
Euphoria severity	0 (0 to 1.5)	0 (0 to 0)	0 (0 to 0)	0 (0 to 0)	9.91*	0.019
Apathy severity	3 (0.5 to 3)	3 (0 to 3)	2 (1 to 3)	1 (1 to 2)	19.17*	< 0.0001
Disinhibition severity	3 (0 to 3)	1 (0 to 3)	0 (0 to 2.5)	0 (0 to 2)	23.85*	< 0.0001
Irritability severity	3 (0 to 3)	3 (0.5 to 3)	2 (1 to 2)	1 (1 to 2)	30.28*	< 0.0001
Motor Disturbances severity	0 (0 to 3)	0 (0 to 3)	0 (0 to 2)	0 (0 to 2)	7.31ns	0.063
Night time behavior severity	2 (0 to 3)	0 (0 to 3)	0 (0 to 1)	0 (0 to 1)	30.91*	< 0.0001
Appetite changes severity	0 (0 to 2)	0 (0 to 2)	0 (0 to 0)	0 (0 to 0)	34.82*	< 0.0001

N=61

Friedman's test *p<0.05

Table 3: Comparison of BPSD distress scores before and after the implementation of mhGAP module

Variables	Pre test Median (IQR)	6 weeks Median (IQR)	3 months Median (IQR)	12 months Median (IQR)	χ2#	p value
Delusion distress	5 (0 to 5)	3 (0 to 4)	2 (0 to 3)	0 (0 to 1.5)	56.10*	< 0.001
Hallucination distress	0 (0 to 5)	0 (0 to 3)	0 (0 to 2)	0 (0 to 0)	21.00*	< 0.0001
Agitation distress	5 (0 to 5)	3 (0 to 4)	2 (0 to 3)	1 (0 to 2)	49.02*	< 0.0001
Depression distress	3 (0 to 5)	2 (0 to 4)	0 (0 to 3)	0 (0 to 1)	50.99*	< 0.0001
Anxiety distress	5 (0 to 5)	3 (0 to 4)	2 (0 to 3)	0 (0 to 2)	61.8*	< 0.0001

Cont... **Table 3: Comparison of BPSD distress scores before and after the implementation of mhGAP module**

Euphoria distress	0 (0 to 0.5)	0 (0 to 0)	0 (0 to 0)	0 (0 to 0)	11.44*	0.010
Apathy distress	5 (0 to 5)	3 (0 to 4)	3 (1 to 3)	1 (0 to 2)	40.11*	< 0.0001
Disinhibition distress	3 (0 to 5)	1 (0 to 4)	0 (0 to 3)	0 (0 to 1.5)	33.06*	< 0.0001
Irritability distress	5 (0 to 5)	3 (0.5 to 4)	2 (1 to 3)	1 (0 to 2)	41.06*	< 0.0001
Motor disturbances distress	0 (0 to 5)	0 (0 to 3.5)	0 (0 to 2)	0 (0 to 0)	21.78*	< 0.0001
Night time behavior distress	1 (0 to 5)	0 (0 to 3)	0 (0 to 1)	0 (0 to 0.5)	29.74*	< 0.0001
Appetite changes distress	0 (0 to 2.5)	0 (0 to 2)	0 (0 to 0)	0 (0 to 0)	32.07*	< 0.0001
Caregiver burden	41 (25.5 to 54.5)	42 (33.5 to 53.5)	36 (27 to 46)	15 (6 to 28.5)	81.07*	< 0.0001

Friedman's test *p<0.05

Discussion

The findings of this study reveals an extensive yet cost effective impact of mhGAP module on managing BPSD and caregiver burden among community dwelling patients with dementia. Systematic reviews and clinical practice guidelines recommended that NPIs are to be preferred in managing BPSD[13,14].In current study, we tested the effectiveness of an NPI based modified mhGAP module on BPSD and burden among patients and caregivers living in a rural community. In comparison, this finding is significant with a number of studies from several countries like Ethiopia, Nigeria, Pakistan and Sri Lanka[12] where mhGAP was found effective. So, this study is adding to the existing evidence that mhGAP module is suitable for low and middle income countries in training health workers and managing patients at community itself.

Current study reported delusion, apathy and agitation as most common, which is coherent with previous study findings[15, 16, 17].There are findings that motor disturbances[18] were also common but our findings did not support this. Regarding caregiver burden, we got a mean ZBI score of 42.25 which was found as high compared to the previous studies[15,19,20.] This could be because of social factors operating in India, where caregivers are predominantly females who are also responsible for household works and rearing children.

Current study demonstrated significant improvement in all domains of BPSD except motor disturbances among patients who received mhGAP interventions. Since this method is cost effective in terms of money and manpower and has a larger impact on community with minimal training of nonprofessionals, policy makers can focus on this area to widen the reach of dementia care. Evidences also support community interventions which resulted in less burden and institutionalization[21]. The common trend of decreasing BPSD over 12 months was observed and it also could be because the caregivers might have learned to handle BPSD over time. Another reason could be that when patient gets weak or bed ridden, BPSD may be less expressed and they will not be able to force caregivers to act on BPSD. In spite of all these factors considered, there was a significant reduction in BPSD after implementing mhGAP module and the researcher recommends that all caregivers must be trained in managing BPSD.

The caregiver burden scores showed a slight increasing trend initially in six weeks and later considerably reduced from six months to one year as a result of mhGAP interventions. The initial increasing

trend could be attributed to the fact that when the caregivers recognize BPSD for the first time, they feel more burdened. Subsequent decreasing trend in burden is observed as the caregiver learned to manage BPSD as the result of mhGAP interventions. It is also postulated that when the patients become physically weak and bed ridden over months, they mostly need palliative care and caregivers are less engaged, and they can divert to other activities which patient could not interfere which might have resulted in less burden.

From the post hoc analysis, it was observed that most of the significant changes in BPSD and burden happened during pretest to 12 months and 6 weeks to 12 months. Hence it can be interpreted that long term interventions are more effective than short term interventions to manage BPSD and burden. This study suggests training of all CHWs in long term dementia management for patients' living in community. Thus the study proves the effectiveness of a community based model for management of dementia patients in low and middle income countries.

The present study has the limitation of quasi experimental design as there was no control group. But quasi-experimental study strategies are commonly utilized in the studies testing effectiveness of intervention programs when random assignment is not feasible. Another limitation was purposive sampling which might have introduced a selection bias which limits the generalizability of findings.

Conclusion

The findings of this study highlighted the need of community based strategies to improve dementia care in rural communities. Low and middle income countries need to focus on cost effective NPI based interventions and training of non specialists to manage dementia patients in the community.

Conflict of Interest: NIL

Source of Funding: Self

Ethical Clearance : The research proposal was submitted to the institutional ethics committee and obtained permission. (IEC NO.B1/312/2015/ CONTSR(2) Dated 15.07.2015). Written informed consent from patients and caregivers were obtained.

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