DYNAMIC LIGHT AND DEMENTIA

THE IMPACT OF DYNAMIC LIGHT EXPOSURE ON SLEEP AND WELL-BEING IN CARE AND HOME SETTING

ELLEN VAN LIESHOUT - VAN DAL

DE RECHTEN VOOR DE AFBEELDING OP MIJN PROEFSCHRIFT ZIJN DOOR DE BELANGHEBBENDEN ALLEEN VRIJGEGEVEN VOOR DRUKWERK, DAAROM ONTBREEKT DE AFBEELDING OP DEZE VERSIE

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Jan Andriesse (1950-1921) was een kunstenaar die gefascineerd was door licht en kleur. Hij zei over licht: 'Het is zuurstof, het is ruimte, het verandert, het leeft. Je kunt bijna zeggen dat licht beweegt'. Die bewegingen van licht probeerde de schilder met wetenschappelijke precisie in verf te vatten. Zo schilderde hij 'Regenboog' bij daglicht. Het was pas af toen hij de koele tonen van de ochtend en de warme tonen van de middag in zijn werk gevangen had. Het is een wonderbaarlijke ervaring om langzaam langs dit panoramisch kleurenspectrum van Jan Andriesse in museum De Pont in Tilburg te lopen. Het lijkt dan alsof de heel geleidelijke kleurveranderingen niet op het doek plaatsvinden, maar in het oog van de beschouwer.

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Promotores
prof. dr. I.M.B. Bongers (Tilburg University)
prof. dr. ir. Y.A.W.D. de Kort (Eindhoven University of Technology)

Copromotor
dr. ing. L.J.A.E. Snaphaan (Tilburg University)

Leden promotiecommissie
prof. dr. S.P.J. van Alphen (Tilburg University)
prof. dr. H.S.M. Kort (Eindhoven University of Technology)
prof. dr. F.R.J. Verhey (Maastricht University)
prof. dr. M.E. de Vugt (Maastricht University)
prof. dr. E.J.M. Wouters (Tilburg University)

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CHAPTER 1
GENERAL INTRODUCTION

Light is present in all of our lives, yet the importance of light in supporting our physiological and psychological functioning is easily underestimated. Light not only enables us to perform daily activities, such as reading and writing, and prevents us from falling. Light also affects our well-being and health, such as our sleep-wake pattern, mood and behaviour. Dementia is a syndrome that has a significant impact on well-being and health and poses several challenges for the patient, for their caregivers and for society. Among these challenges are also those related to sleep-wake, mood and behaviour. Disturbances in the sleep-wake pattern, mood and behaviour are often treated with pharmacotherapy, which can cause negative side effects and may even worsen symptoms. Light is a promising non-pharmacological intervention and has no side-effects.

In this thesis, we study whether and in which way we can best support people with dementia still living at home with a suitable, applicable, and non-burdensome intervention such as transportable dynamic light.

1. DEMENTIA: CHALLENGES AND OPPORTUNITIES

1.1 GLOBAL AND SOCIETAL CHALLENGES IN DEMENTIA

Dementia is a syndrome associated with a continuous decline of brain functioning. Alzheimer's disease is one of the most well-known forms of dementia and, together with vascular dementia, accounts for the majority of cases (Alzheimer's Association, 2022). Dementia presents a societal and global challenge, as more than 55 million people in the world live with dementia (WHO, 2021). The long-term dementia strategy of most Western governments focuses on encouraging people with dementia to live at home as long as possible instead of going to long-term care settings such as a nursing home (Ministry of Health, Welfare and Sport, 2020). But people with dementia and their loved ones themselves generally also wish to continue living in a familiar and trusted environment and to receive appropriate support and care in the home situation for as long as possible (Sury et al., 2013; Harrison et al., 2019). It is therefore important to find out what causes a transition from home to a nursing home. Moreover, it is important to learn how people with dementia and their family caregivers can be supported in the home situation to be able to delay this transition from living in the community to living in residential care as long as possible. To support this mission, one of the themes addressed in the dementia strategy is innovation. This includes, for example, the use of technology as well as the development of suitable innovative methods for people with dementia to continue functioning as valuable members of society. This global and societal focus on supporting people with dementia at the community level also implies the need to study the effectiveness of various innovations in a home environment.

1.2 PERSONAL CHALLENGES IN DEMENTIA

Besides being a global and societal challenge, dementia is a personal challenge. Dementia negatively affects the general quality of life of people suffering from the disease and of their family caregivers, as dementia, on top of the decline in memory and cognitive functioning, is accompanied by various behavioural and psychological symptoms (BPSD), also referred to as neuropsychiatric symptoms. Over 90% of persons with dementia experience one or more of these BPSD throughout the course of their disease (Cerejeira et al., 2012). BPSD are strongly associated with caregiver burden, increased medication use and increased risk of nursing home placement (Livingston et al. 2017; Toot et al., 2017).

The most common BPSD are depression, anxiety and agitation. Depression is a significant precursor of dementia, and once people have dementia, it can worsen symptoms of depression (Korczyn & Halperin, 2009; Snowden et al., 2015). The prevalence of depression in dementia is estimated at 40% (Kitching, 2015). The prevalence of anxiety in dementia varies from 8% to 81%. The prevalence of agitation ranges from 60% in people with mild cognitive impairment (MCI) to 76% in people with dementia Van der Mussele et al., 2015). The large variance in these estimates may be due to the difficulty in operationalizing anxiety separately from symptoms such as depression and agitation in dementia (Kaiser et al. 2014). But prevalence of BPSD also shows variance with living situation. A systematic review and meta-analysis of Toot et al. (2017) showed that people with dementia admitted in a nursing home showed significantly more BPSD than those who remained at home. Furthermore, a recent study of Djekovic et al. (2022) explored the nature and severity of BPSD and outcomes for patients admitted to a specialist dementia care unit (SDCU) at a hospital. Their study revealed that multidisciplinary management, including an individualised approach with caregiver involvement, a supportive secure environment, and skilled staff, led to an overall reduction in BPSD severity. Subsequently, this helped facilitate the transition of patients with BPSD from the hospital back to a home setting. On the one hand, these results confirm the high risk of transition to a nursing home for people with BPSD, on the other, the results emphasise the importance of a multidisciplinary and individualised approach to manage BPSD.

Another important reason for the transition to a nursing home are sleep disturbances (Hjetland et al., 2020). Sleep disturbances occur as primary BPSD. However, they also occur secondary to other BPSD, such as depression, anxiety and agitation, and may exacerbate these symptoms, especially at night (Hjetland et al., 2020). Up to 70% of people with dementia experience clinically significant sleep disturbances, such as nighttime wandering, sleeplessness, being awake at night, and daytime napping (Webster et al., 2019). Sleep disturbances are linked to poorer disease prognosis (Wennberg et al., 2017).

1.3 OPPORTUNITIES OF LIGHT THERAPY IN DEMENTIA

Our internal biological clock, located in the suprachiasmatic nuclei (SCN) in our brain, is responsible for regulating the circadian rhythm (sleep-wake pattern) based on the retinal light signals (Blume et al., 2019). Dementia can exacerbate normal ageing processes. As a result, people with dementia often have damaged cells in the SCN and decreased cellular activity in this part of the brain (Gehrman et al., 2005). Moreover, as one grows older and especially in dementia, light sensitivity is reduced by the eye lens' thickening and yellowing (Hood & Amir, 2017). This disrupts the biological clock which causes sleep disturbances. As shown in Figure 1, sleep disturbances can intensify BPSD, and BPSD can intensify sleep disturbances resulting in a lower quality of life (Hjetland et al., 2020; Zhou et al., 2019). Simultaneously, this figure shows the promising opportunity of light therapy to support people with dementia suffering from BPSD and sleep disturbances.

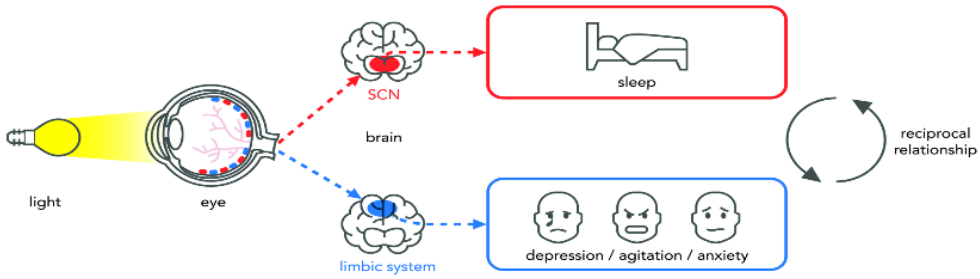

Figure 1. The direct and indirect relationship between light, sleep and BPSD (figure adjusted from Fernandez et al., 2018)

1.3.1 Light therapy for BPSD

Research has shown that light therapy, when properly designed and implemented for older adults, can improve BPSD in people with dementia (Goudriaan et al., 2021; Jao et al., 2022). Based on a literature review, Hanford and Figueiro (2013) recommend that exposure to a light intensity of >1000 lux (depending on the exact spectrum) for at least two hours a day and low light levels in the evening would result in a positive effect on the sleep pattern and reduced symptoms of depression in people with dementia. A study by Onega et al. (2018) also revealed that bright light therapy (10,000lx, 30 minutes twice a day, five days per week for eight weeks) significantly reduced anxiety symptoms in older adults with dementia. This finding is consistent with the finding of Forbes et al. (2014), who concluded in their meta-analysis that there is evidence on the positive effect of light therapy on anxiety symptoms in people with dementia.

Furthermore, research shows that dynamic light exposure may be beneficial in alleviating *agitation* in people with dementia. Dynamic light is carefully designed to maximally affect the circadian system by simulating a regular daylight curve in light intensity, spectrum, timing, and duration. Wahnschaffe and colleagues (2017) performed a study in the midwinter and winter season in which a ceiling mounted dynamic lighting system was installed in the common room of a nursing home and programmed to produce high illuminance with higher blue light proportions during the day and lower illuminance without blue light in the evening for four months. They found that this significantly reduced agitated behaviour in people with dementia. Figueiro et al. (2014, 2019) also showed that a dynamic lighting intervention improved symptoms of depression and agitation in patients with dementia in a nursing home within four weeks of exposure.

1.3.2 Light therapy for sleep disturbances

Due to ageing, eyes undergo various physical changes, such as reduced visual ability and contrast sensitivity, diminished glare and light dark adaptation (Shikder et al., 2012). Dementia intensifies these eye related changes which changes the visual requirements in older people with dementia. For instance, the illumination requirement of an 80-year old equals ten times of a young adult's requirement (Nioi et al., 2017). Due to that reason, older people may be exposed to very low levels of illuminance. Insufficient illuminance levels contribute to sleep disturbances (Eilertsen et al., 2016). Research has shown the potential positive effects of light therapy, when properly designed and implemented, in treating sleep disturbances in people with dementia, however mainly studied in institutional contexts and not in home settings (Hjetland et al., 2020; Jao et al., 2022; van Maanen et al., 2016; Sekiguchi et al., 2017).

1.4 CHALLENGES OF LIGHT THERAPY AND RESEARCH AT HOME

Despite the clear potential of lighting systems designed to stimulate the circadian rhythm that could influence the quality of life for people with dementia living at home, previous studies yielded mixed results on how to reliably and validly develop more precise clinical guidelines on the exact use of light interventions (Hjetland et al., 2020; Kompier et al., 2020; Yao et al., 2022). Challenges are that previous studies show a large heterogeneity in terms of the timing and duration of the offered light scenario, the technological light specifications, the study design and analysis of the results (Mitolo et al. 2018), and often lack a complete description of the apparatus and light scenarios. This makes studies difficult to compare. Most studies also do not control for seasonality nor describe the possible impact of confounders like received natural daylight while it is known that light values indoors cannot compete with those of natural daylight (Shirani and St Louis, 2009; Sekiguchi et al., 2017; Knoop et al., 2020). Furthermore, most light systems used in studies conducted in nursing homes are not suitable for, or transportable to, studies in home situations. For example, the installation of such lighting systems is expensive

because they may need structural changes to the place where they are being installed, reducing their feasibility in home settings (Riemersma-van der Lek, 2008). Besides installation or transportation difficulties, most studies use standard light therapy methods, like light boxes. However, due to the increased sensitivity of the ageing eye to discomfort glare and blinding by light, standard light therapy methods are not appropriate as they are not adapted to the needs and preferences of older adults (Konis et al. 2018). Dynamic light exposure seems a more suitable alternative for older adults, especially people with dementia, as it allows for free movement and enables continuing daily activities. Moreover, it may more comfortably support the diverse lighting needs of this population and causes no visual discomfort (Goudriaan et al., 2021; Kunduraci et al., 2017). Unfortunately, dynamic light exposure is mainly studied in institutional contexts and not in home situations (Lieverse et al. 2011; Figueiro et al. 2015; 2019; 2020).

Another challenge is that it is complex to conduct studies in a home setting because of the heterogeneity of the population. For instance, people with dementia tend to spend more time indoors than outdoors. Various indoor settings portray different living circumstances, such as the number and size of windows, curtains, and ceiling height, which determine the amount of natural light that flows into the house during the day. In addition, people with dementia in the home environment are mostly supported by family caregiver(s) who are not trained as researchers. Their knowledge levels about the patients' condition may differ, as well as their ability to use measurement devices such as wearables. Moreover, dementia is a progressive disease and symptoms may deteriorate and impact caregivers' capacity to cope.

The challenges explained here demonstrate a need to perform more methodologically robust real-life field studies to ascertain the actual effectiveness of light therapy and how much value it provides to patients and caregivers at home. A suitable study design needs to take into account that living circumstances, daily routines, the type of dementia, time since diagnosis and other personal characteristics differ per participant. This heterogeneity makes it difficult to conduct a randomised controlled trial (RCT) – the typical gold standard in clinical research, whereby patients are assigned to control and intervention groups for comparison purposes. Therefore, other methodologies need to be considered. A Single Case Experimental Design (SCED) in a real-life field study could be suitable for taking many of these inter-individual variabilities into account. The ecological validity of SCED-design studies is considered high. It controls for individual nonspecific treatment effects. Of course, not every non-specific effect can be controlled for, however it can be accurately described. Future studies that provide a complete description and motivation of the offered light scenario (including timing and duration), the used study design, and that control for confounders like seasonality, are needed to gain a better understanding of the effectiveness of light therapy in people with dementia.

1.5 RESEARCH OBJECTIVES AND THESIS OUTLINE

The current thesis aims to fill the knowledge gap on the effectiveness of a transportable dynamic light system, suitable for home use, on the sleep pattern and BPSD of people with dementia in a clinical and home setting. First, the implementation of a study in a clinical setting shows the possibilities and limitations in studying this population. This knowledge and experience laid the groundwork to feasibly design and implement a real-field study by controlling for different personal and living circumstances and other methodological requirements. Subsequently, experiences of implementing a study investigating the effectiveness of dynamic light therapy in a home setting are documented.

Five research questions were addressed:

Research Question 1: Is it possible to expose people with dementia to significantly more light in a clinical setting using a transportable dynamic light system?

Research Question 2. Can a transportable dynamic light system have a positive effect on the sleep pattern and BPSD of people with dementia in a semi-controlled clinical setting?

Research Question 3. Can the knowledge and experience obtained in the semi-controlled clinical setting result in a study design suitable and applicable to study the complex heterogenic population of people with dementia living at home?

Research Question 4. Is it possible to expose people with dementia living at home to significantly more light by a transportable dynamic light system?

Research Question 5. Can a transportable dynamic light system have a positive effect on the sleep pattern and BPSD of people with dementia living at home?

These five questions aim to feed the overall objective of creating an understanding about supporting people with dementia with light therapy for home use.

In **Chapter 2**, we investigated whether a transportable dynamic light system suitable for home use offers significantly more light exposure when present in a semi-controlled clinical setting. In addition, we investigated if this system could positively affect the sleep-wake pattern of admitted people with dementia. Our research protocol investigated the differences in light

exposure in a regular light (A) and dynamic light condition (B); each condition lasted four weeks in an ABAB setup and assessed the sleep-wake pattern objectively with a bed-sensor mattress. Subsequently, in **Chapter 3**, we investigated, in the same study sample, whether the used dynamic light system impacted BPSD. Therefore, residents' symptoms were structurally assessed with validated questionnaires by their healthcare professionals. In addition, these healthcare professionals scored the severity and emotional impact of these symptoms on themselves. These studies provided new insights regarding the complexity of studying such a heterogeneous population of people with dementia. In **Chapter 4**, we used the lessons learned about our research protocol and investigated how a real-life SCED research design, using several wearables for data collection, might be suitable and applicable to objectively study dynamic light exposure in people with dementia living at home with an informal caregiver. In **Chapter 5**, we investigated how the used transportable dynamic light system could affect the sleep-wake pattern and BPSD in people with dementia living at home.

These in context field studies taught us several important lessons in studying dynamic light exposure in people with dementia. In the last two chapters of this manuscript, the unexpected situations we had to cope with are extensively described. We provide an overview and discussion of the findings, including recommendations for future research and practical implementation of light therapy in **Chapter 6**. Finally, we conclude with a comprehensive general discussion in **Chapter 7**.

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CHAPTER 2

BIODYNAMIC LIGHTING EFFECTS ON THE SLEEP PATTERN OF PEOPLE WITH DEMENTIA

E.E. VAN LIESHOUT - VAN DAL
L.J.A.E SNAPHAAN
I.M.B. BONGERS

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ABSTRACT

Dementia can disturb the circadian rhythm more than in normal ageing people. And their biological clock is often not sufficiently stimulated by light. Sleep disturbances form a high burden for informal caregivers and is the main reason for institutionalisation. The effect of biodynamic lighting with varying intensity and colour resembling a daylight curve has hardly been objectively researched. In this study, we evaluate the exposure to biodynamic lighting on circadian functioning of 13 patients with dementia admitted to a psychiatric hospital. Three biodynamic lighting armatures designed for home use were placed in the common area for a period of three weeks and then removed for the same period. These periods were intermittent in an AB-phase design. Objective data of the sleeping pattern were collected using a bed sensor. During exposure the average frequency of night-time bed wandering significantly decreased from 11 to 5 times (P=0.002). The average frequency of daytime napping significantly decreased from 16 to 7 times (P=0.004). The average total night-time sleep significantly increased from 408 to 495 minutes (P=0.007). The average total time out of bed at night significantly decreased from 180 to 104 minutes (P=0.006). This pilot study found promising evidence (effect sizes >0.5) that biodynamic lighting, tailored to stimulate circadian entrainment, could be helpful in decreasing sleeping disturbances in patients with dementia. This biodynamic lighting setup could easily be used as a non-pharmacological intervention in a home situation.

2.1 INTRODUCTION

The number of people living with dementia worldwide is currently estimated at 35.6 million. This number will be doubled by 2030. Dementia is the leading psychiatric condition for people over 60 (WHO, 2012). It is of great importance that older people with dementia stay as healthy and vital as possible so that their quality of life remains high. In turn, it will also reduce the number of people going to care homes. Innovative care models for people living with dementia are promising to be effective in improving their health, quality of life and reducing care homes admission rates. One of these innovations is lighting (Desai et al., 2001; Van Hoof et al., 2017; Zeisel et al., 2003;).

Lighting has important visual but also non-visual aspects as light synchronises physiological and behavioural rhythms in our body and influences the biological clock (Ramkisoensing et al., 2015) which is located in the suprachiasmatic nucleus (SCN) in the brain. The SCN stimulates the production of sleep-wake hormones (cortisol and melatonin) and follows a circadian rhythm. Warm colour temperatures are associated with stimulation of the secretion of melatonin, also known as sleep hormone. Cool colour temperatures are associated with the inhibition of melatonin and stimulation of the production of cortisol. This hormone is responsible for alertness and activity during the day (Aries et al., 2010; LeGates et al., 2014). The effectiveness of light on the biological clock depends on several factors, such as light-intensity (≥1000 lux) (Riemersma-van der Lek et al., 2008), colour temperature (>4500 Kelvin) (Van Hoof et al., 2009), colour rendering index (CRI) and the absorption spectrum of the lighting sources. Due to sensitivity for the light spectrum and a greater sensitivity for the blinding of light (due to degeneration of the ganglion cells) several light therapy methods are not suitable nor appreciated by older people (Aries et al., 2010). Older people between 62 and 76 years of age best appreciate a lighting intensity level around 1000 lux (Davis & Garza, 2001) and are more sensitive to indirect light.

Dementia can disturb the biological clock even more than in normal ageing. Several mechanisms have been postulated for this effect such as a more severe degeneration of the retinal ganglion cells and greater loss of functionality of the biological clock located in the suprachiasmatic nuclei. Therefore, people with dementia are at increased risk for a distortion of the circadian rhythm. In addition, people also tend to go less outside when they get older, especially people with dementia, so the biological clock is less stimulated by light. On the average young people spend five hours a day outside, older people 1 hour and people with dementia in a nursing home only 1,6 minutes. In combination with the age-related optical changes to the eye, particularly smaller pupils and denser lenses, older people need far more light input than younger people (Figueiro et al., 2015; Revell & Skene, 2010). They are actually double handicapped (Aarts & Westerlaken, 2005). Furthermore, numerous studies show that the indoor light conditions in home or nursing care facilities for the older people are

not sufficient for the visual and the non-visual aspects of light (Hazenberg & Stoer, 2006; Riemersma-van der Lek et al., 2008; Sloane et al., 2008).

All these together leads to a biological clock that is not stimulated enough by light, which can have huge consequences for the person with dementia and the informal carer. The disruptions of the circadian rhythm can lead to problems in the sleeping pattern manifested in symptoms such as nightly wandering, daytime sleepiness and daytime napping (Nolan et al., 2003). These symptoms form a high burden for caregivers and are among the main reasons for institutionalisation. It increases the chance of hospitalisation ten times Abbott, 2003; Hatfield et al., 2004; Harper et al., 2005; Riemersma, 2004).

Several studies have demonstrated that light is a promising non-pharmacological intervention to improve the sleeping pattern of older people with and without dementia. A review study of White et al. (2013) including 18 cited articles of randomised controlled trial studies, concludes that dynamic lighting interventions may mitigate symptoms of circadian disruption in older people living in senior living environments.

Not all studies show a significant positive effect of light exposure in people with dementia. Van Hoof and colleagues (2013), and Forbes and colleagues (2014) both conclude in their review articles that there is limited statistical proof for the health effects of daylight. Fontana Gasio et al. (2003) did not see an effect of a dawn simulator on circadian rhythm disturbances in people with dementia. Sloane et al. (2015) also did not see a significant effect of a tailored lighting system on measures of sleep in people with dementia, however they did demonstrate a significant improvement in sleep quality in the caregivers. Both authors hypothesised that the used light sources did not seem to have a high enough light output to stimulate circadian entrainment. A field study of Aarts et al. (2018) confirms this hypothesis as they found a significant effect of high illuminance natural daylight exposure in summer on the sleep of healthy older people but did not find an effect in winter.

Not only the illuminance quantity, but also the spectrum of visible light is an important factor in light exposure. The different wavelengths of the visible light spectrum are seen by the eye as different colours. The use of short-wavelenght light (460-470 nm), also referred to as bluish light, lowers the threshold for circadian stimulation (Figueiro et al., 2011). In addition to quantity and spectrum, the timing and duration of light exposure are also important. Light affects this system for the full 24 hours in a day (Figueiro et al., 2018). It is important to note that the authors of both review articles analysed studies that used a variety of light therapy approaches and it is not clear how the light doses received by the participants were measured or monitored. Figueiro et al. (2015) extends the studies by Sloane et al. (2015) and Figueiro et al. (2014). They used light sources with a high short-wavelength (bluish) and high light output in the

homes of people with dementia and found that this lighting intervention significantly increased sleep time and reduced depression and agitation scores. The authors then observed that people with dementia in nursing homes spend much time in the common area and tested the effectiveness of a light table and found positive effects on sleep quality and mood after four weeks of exposure (Figueiro et al., 2016). Recently, Figueiro et al (2018) state that it is one of the biggest challenges to find a practical method for effectively delivering the lighting intervention to the eyes of people with dementia. Our study takes this into account by using a floor lamp that is designed for home use. This lamp exposes people to biodynamic lighting, lighting that follows a daylight curve in intensity, spectrum and temporal characteristics, to stimulating circadian entrainment. The lamp produces direct and indirect light with a high illuminance and bluish colour (high short-wavelength content) in the morning and lower levels in the evening. In order to make the robustness of the results of our study as optimal as possible, we have chosen a within subjects design and performed the study in an inpatient ward. Often results are obtained through subjective sleeping questionnaires or studies that show a lot of diversity in participants and used lighting programmes. In this study objective measures are used to obtain results.

The aim of this study is to investigate if biodynamic lighting, resembling a normal daylight curve in light intensity and colour in a fixed programme, objectively improves the sleeping pattern of institutionalised patients with dementia.

2.2 MATERIALS AND METHODS

2.2.1 Participants

The participants were recruited from a treatment facility for patients with neurocognitive disorders in psychiatric hospital GGzE in Eindhoven, the Netherlands within the period of January 2016 to January 2017. The attending physician and the formal caregivers working at the ward identified potential participants for the study. The inclusion criteria for the study were a primary diagnosis of dementia diagnosed by a geriatrician, neurologist or psychiatrist, based on the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) (APA, 2000) criteria. We excluded patients from participation in the study if diagnosed with any other neurological disorder, including narcolepsy, sleep apnoea or restless legs syndrome or a serious eye disease incompatible with light therapy, such as retinitis pigmentosa. Patients were also excluded if they were physically disabled or if their acute psychiatric condition was not suitable for participation, like a manic episode, addiction or severe aggression in a psychotic episode. No restrictions are made for medication use. During the study medication was monitored.

The study protocol was approved by the internal scientific review committee of the psychiatric hospital GGzE. All participants signed a written informed consent to participate in this study, according to the Declaration of Helsinki (Seoul Revision, 2008) and the General Data Protection Regulation (AVG) www.eugdpr.org. Applies in 2018.

2.2.2 Procedure

2.2.2.1 Lighting intervention

Three biodynamic lighting armatures were placed in the common room of the ward. In biodynamic lighting the illuminance level and the colour temperature are combined in the right proportion and varied throughout the whole day from 7:30 am to 10:30 pm resembling a daylight curve. All these aspects are accounted for in the designation of the Sparckel, type Bright Brenda (Sparckel, 2018). This lamp has been developed after extensive research in a co-production with lighting specialists and users. A fixed daycurve programme was installed and used in our study. Figure 1 illustrates the situation in a clinical ward of GGzE and figure 2 shows the floorplan of the used common room with the location of the three biodynamic lighting armatures.

Figure 1. Patient exposed to biodynamic lighting

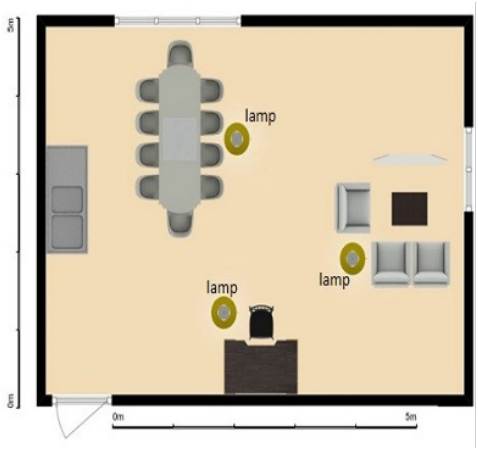


Figure 2. Floorplan of the common room

One lamp can produce up to 7500 lumen, five times more than usual in an office or living room. It also produces a colour temperature of 2700-6500 Kelvin (indirect-direct) and the spectrum of the biodynamic lighting simulates a regular daylight curve by following this curve in light colour and intensity. There is no risk of blue light hazard and no exposure to UV-radiance. Other important data like the Colour Rendering Index and the Melanopic Effect Factor from the measurement report (Olino, 2017) are shown in table 1.

Table 1. Measurement data of one lamp from Olino measurement report

Parameter	Lamp measurement	Remark
Colour temperature	4847K 4750K	Direct light Indirect light
Light intensity	1984.2Cd	0,1m distance
Colour Rendering Index	87	CRI_Ra
S/P ratio	2.0	1m distance
Melanopic Effect Factor	0.682	According to standard DIN SPEC 5031-100:2015-08
Light spectrum	465-480 Nm	Melanopic lux
Luminous Flux	6818lm	1m distance
Blue light hazard risk group	0	No risk

A close-up from the topside and screen of the lamp is shown in figure 3. The topside of the lamp produces indirect light and contains 12 high power LED lights producing a maximum of 3 watt per piece. It consists of 4 lights producing 6500K, 4 lights producing 2700K and 4 lights producing 1800K. The bottom side produces direct light and contains 196 medium power Led lights producing a maximum of 0,3 watt per piece. It consists of 98 lights producing 6500K, 49 lights producing 2700K and 49 lights producing 1800K.

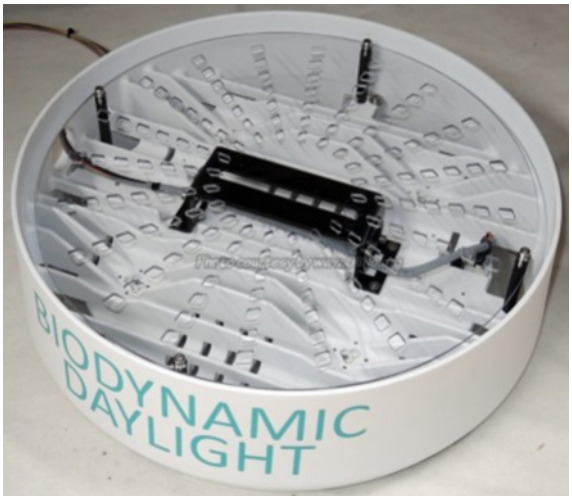


Figure 3. Topside of the lamp

Because of the sensitivity of the older eye, we dimmed the exposure to 75%, to increase the comfort of the patients. The distance between the light hood and the eyes of the participant is between 760 and 860 mm. During the day the participants gradually received light intensity from 600 lux at 8 am, 1100 lux from 10 am till 2 pm and 600 lux at 5 pm. The varying colour temperature during the day of the biodynamic lighting lamp is shown in figure 4. During the day the colour temperature is around 6500 Kelvin, bluish light. During the evening, the colour temperature is warm, around 1800 Kelvin.

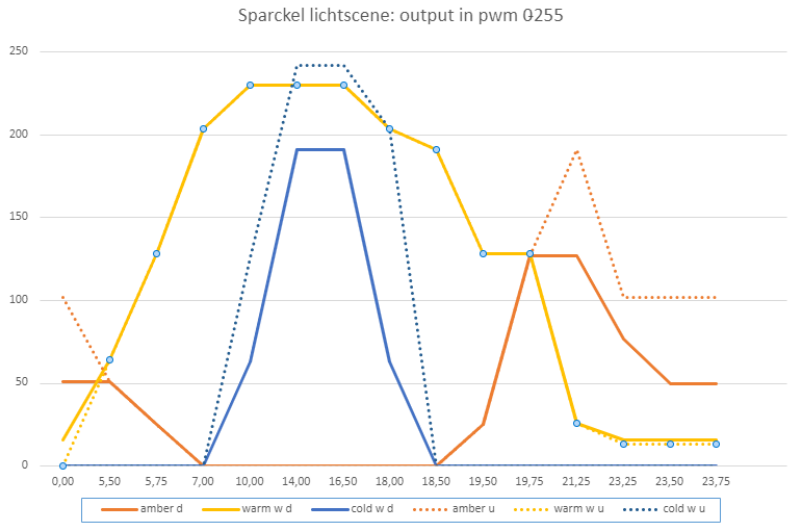


Figure 4. Biodynamic colour temperatures of the Sparckel, type Bright Brenda, during a day

Figure 5 shows the power spectrum, the sensitivity curves and resulting night and day spectra at 1 m distance.

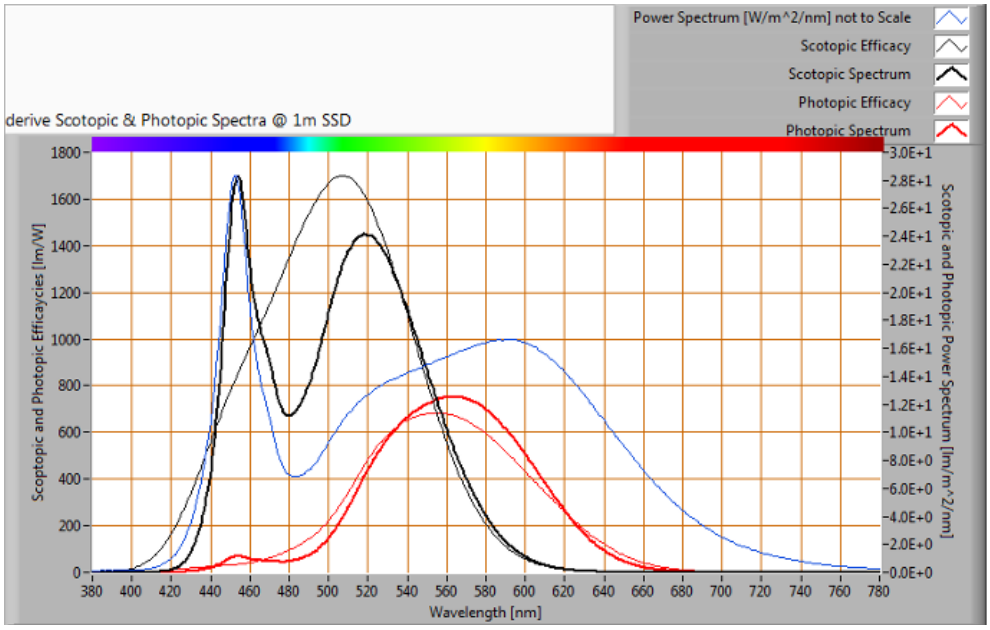


Figure 5. Power spectrum, sensitivity curves and resulting night and day spectra (1 m distance).

2.2.2.2 Lux meter

In order to have objective measurements of the received amount of lighting by the participants, lighting measures were collected. In each condition, the amount of lux was measured manually at least three times a week at three fixed locations in the common room at three fixed moments a day (9:00 AM, 1:00 PM and 5:00 PM). Vertical measurements were obtained at eye level because they approach the real-life situation of light collected by the ganglion cells in the eye the most. The lighting measurements were collected with a Voltcraft MS-200LED-luxmeter. According to the European standards, 500 lux is recommended for adult people, not elderly, to be able to type, read and write (CEN, 2009).

2.2.2.3 Design

The design of this study focused on a within subjects design. The advantage of a within subjects design is that individual differences between participants have no influence as participants are their own control. Participants start in the condition that is present at the moment of admittance. Conditions of exposure to biodynamic lighting (condition A) and no exposure to biodynamic lighting (condition B) are intermittent during a study period of 12 months. All participants will minimally undergo a condition A and B.

The study design is shown in figure 6. Condition A represents exposure to biodynamic lighting and condition B represents no exposure to biodynamic lighting, only regular daylight exposure, both for the duration of 3 consecutive weeks. It takes about 2 weeks to adjust the biological clock in people with dementia. A recent study of Sekiguchi et al. (2017) shows effects of bright light therapy within 2 weeks. To minimize carry-over effects the first two weeks of each condition were marked as wash-out and adjustment period and the last week (3rd week) is used for data collection (Bouter et al., 2010).

A: exposure (3 weeks) **B: no exposure (3 weeks)**

Figure 6. Research design ABABAB

The quality of sleep is determined by outcome measures of the time in bed during day and night, and the frequencies of daytime napping and night-time bed wandering. For this purpose, 6 variables are objectively measured in each condition by the Caremonitor (see figure 7). These variables are 1) frequency of night-time bed leave moments, 2) frequency of daytime moments in bed, 3) time in bed during the night (min), 4) time out of bed during the night (min), 5) time in bed during the day (min), 6) time out of bed during the day (min).

2.2.2.4 Sleep pattern measurements

The sleeping pattern is measured with the Caremonitor (Caredon, 2016). The Caremonitor is a thin mattress with sensors that is placed under the normal mattress of the participant. An example is shown in figure 7.

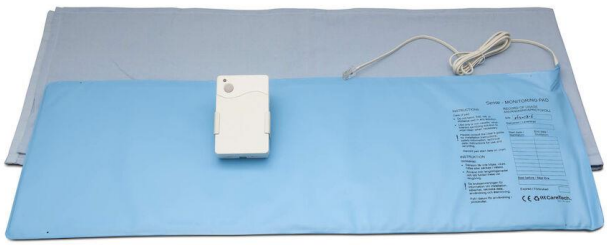


Figure 7. Example of a mattress with a bed sensor

The Caremonitor, produced by Caredon, is CE-certified and available for five years now for health care facilities in different countries. It is a reliable (99,5%) bed exit and wandering detection system developed for the Caremonitor platform. Via a high-tech sensor, discretely placed under the conventional mattress, it is being registered whether a client has left the bed, or hasn't returned to the bed within 5 minutes. Daytime is defined as 7:30 am to 10:30 pm and night-time is defined as 10:30 pm to 7:30 am. It manages to measure the exact frequency and duration of the participant leaving the bed or going to bed by a monitor or pdf-function (Bedleave and Wandering module). A bed leave is registered when a patient leaves the bed for more than 5 minutes. A nap is registered when a patient goes to bed for more than 5 minutes. It should be noted that the sensor does not register if the patient is actually sleeping when lying in bed.

Data are used for five subsequent days and nights in the last week of each condition (Monday-Monday). Medication use and dosage is registered at the beginning and end of participation in the study.

2.2.3 Analyses

Sleep pattern measurements and lighting measurements Data were analysed using SPSS version 19 (SPSS, IBM, Armonk NY). When participants undergo one biodynamic lighting condition (A) and one normal lighting condition (B) a within subjects analysis can be performed. All variables were tested if they were normally distributed to be able to perform a t-test. As none of the variables were normally equated, the Wilcoxon non-parametric test was chosen (two related samples) to analyse the data. The Bonferroni method was used to correct for multiple testing. The significance threshold was set at .01. The data of four participants that completed more than two intermittent conditions were also analysed using the Wilcoxon non-parametric test and are separately described and visually displayed. Effect-sizes were calculated for all statistically significant results. Effect-sizes are considered small for $r < .1$, moderate for $r < .3$ and large for $r > .5$. The effect sizes are calculated conform Cliff's Delta and absolute values are used as described by Conroy (2017).

2.3 RESULTS

2.3.1 Study population

Sixty-one patients and their informal caregivers received information about the research project and were invited to participate. Written consent was obtained from 39 patients, a response rate of 63,9 %. Twenty-six patients did not complete two conditions due to discharge, transition to a specialised nursing home or on account of decease. We obtained complete data of 13 patients. The group includes 7 women and 6 men with a mean age of 74,77 years. Four patients completed more than two conditions. Seven participants started in condition B (no exposure to biodynamic lighting) and six in condition A (exposure to biodynamic lighting).

2.3.2 Outcome measures

The mean amount of lux in the 'biodynamic lighting' condition was 1145,8 lx ± 562,9 lx with a minimum of 385 lx and a maximum of 1900,4 lx. The mean amount of lux in the 'normal lighting' condition was 384,8 lx ± 281,2 lx with a minimum of 63,4 lux and a maximum of 904,3 lux. A two-tailed paired t-test did show a significant difference between the amount of lux in both conditions ($p<0.001$).

Data of five subsequent days and nights in the last week (Monday –Monday) of each condition were collected for each participant. Six sleep pattern variables were studied. Significance (P<.01) was reached in four out of six variables. Conform best practice, effect sizes of each significant result are calculated. The effect sizes of all significant results are $r > .5$. Results are shown in table 2.

Table 2. Results sleep pattern variables in condition A and B

Sleeping pattern variables	***A (SD)***	***B (SD)***	***P***	***r***
Frequency bedleave night	4,75 (2,98)	10,83 (8,78)	0.002*	.610
Frequency daytime napping	7,26 (5,68)	15,97 (12,21)	0.004*	.569
Minutes in bed night-time	495,10 (68,54)	407,84 (79,48)	0.007*	.528
Minutes out bed night-time	103,96 (70,19)	179,64 (89,39)	0.006*	.541
Minutes in bed daytime	166,05 (109,70)	201,59 (143,10)	0.133	
Minutes out bed daytime	678,34 (99,58)	639,15 (144,24)	0.196	

* indicates significance (P<0.01), A = exposure biodynamic light, B = no exposure biodynamic light but normal light

The frequency of bed leaves at night and the frequency of daytime napping both significantly decreased in the biodynamic lighting condition compared to the normal lighting condition.

The duration in bed at night significantly increased in the biodynamic lighting condition compared to the normal lighting condition and the duration out of bed during the night significantly decreased in the biodynamic lighting condition.

The boxplots below show a visual display of the significant results. In figures 8 and 9 the frequencies of bedleaves at night and daytime napping in normal (B) and biodynamic lighting (A) conditions are shown. The frequency of bed leaves at night was significantly less in the biodynamic lighting condition (p=0.002). In addition, the frequency of daytime napping was significantly less in the biodynamic lighting condition (p=0.004).

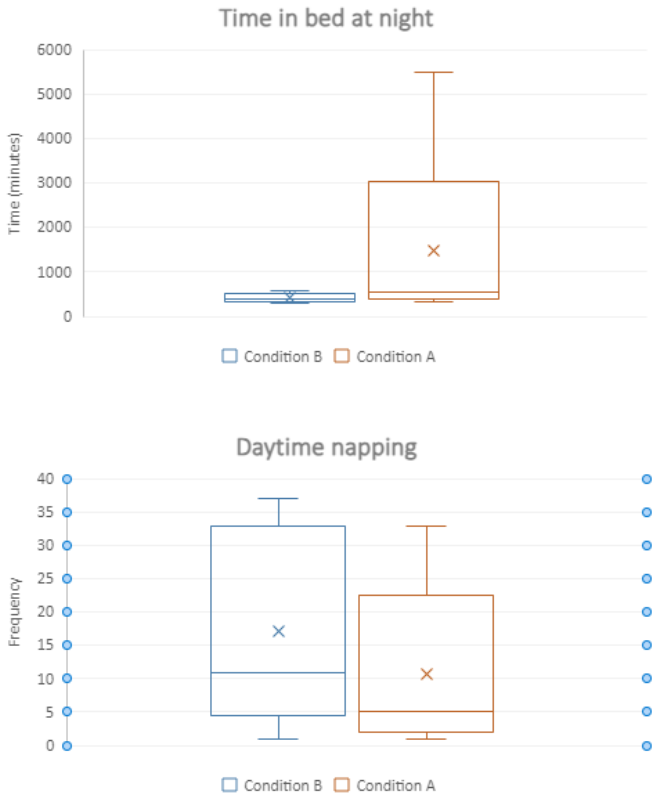
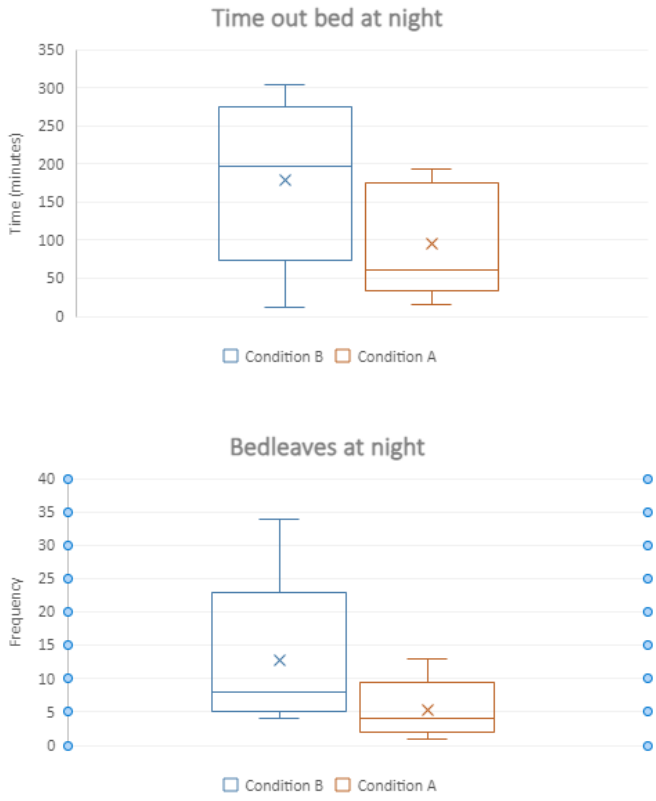


Figure 8 and 9. Frequencies of bed leaves at night and napping during daytime in condition B (normal lighting) and A (biodynamic light exposure)

In figures 10 and 11 the duration in and out of bed during the night is shown. Duration in bed at night was significantly greater in the biodynamic lighting condition (p=0.007). Duration out of bed at night was significantly less in the biodynamic lighting condition (p=0.006).



Figures 10 and 11. Time in and out of bed in minutes during the night (A= biodynamic lighting condition, B=normal lighting condition)

2.3.3 Completion of more intermittent conditions

Although this study focussed on minimal one A and B condition, one participant was admitted to the ward for a longer time and completed six conditions during the pilot following an A1B1A2B2A3B3 order. This data is very interesting because with this data we could also investigate whether the hypothesised effect could be reconfirmed. The results of the participant that completed six conditions are shown in figure 12. A decrease is visible in bed leaves at night and napping during daytime in two biodynamic lighting conditions (A1, A2) compared to the normal lighting conditions (B1, B2).

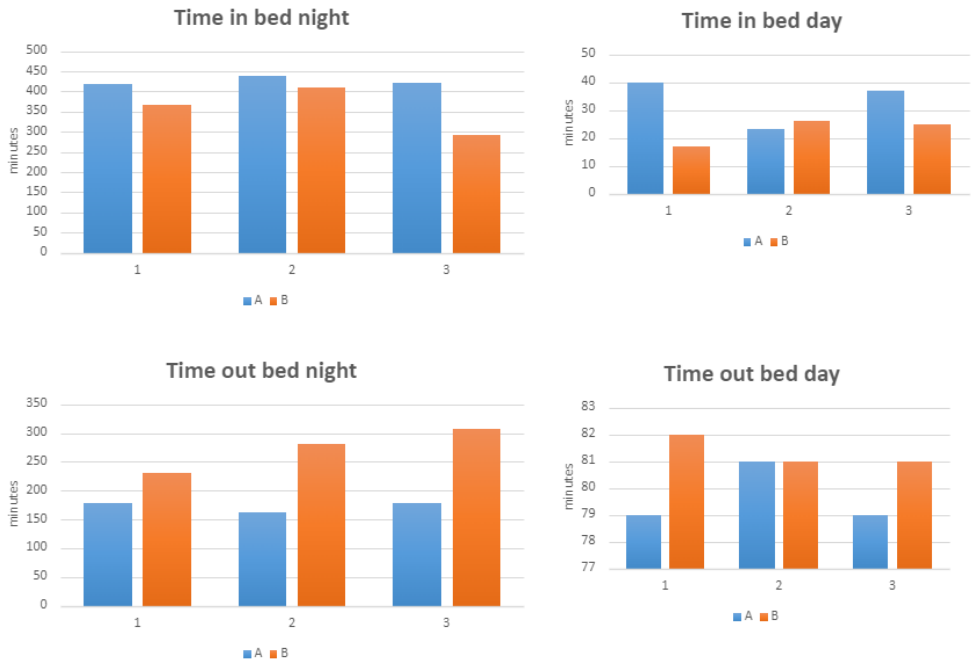


Figure 12. Results of the participant that completed six conditions A1 (biodynamic lighting), B1 (normal lighting), A2 (biodynamic lighting), B2 (normal lighting), A3 (biodynamic lighting), B3 (normal lighting).

The results of the participants that completed three conditions in an A1B1A2 or B1A2B2 order, are visually displayed in figures 13, 14 and 15. In participant 1 and 3 the frequency of bed leaves decreases in the biodynamic lighting condition, increases in the normal lighting condition and decreases again when the biodynamic lighting returns. For participant 2 starting in the normal lighting condition, the frequency of bed leaves increases in the normal lighting condition, decreases in the biodynamic lighting condition and increases again when the normal lighting condition returns. The frequency of daytime napping shows the same pattern in all participants. This is a strong indication of the positive effect of biodynamic lighting on night-time bed leaves and daytime napping. In participant 1 and 2 the same positive effect is visible in the duration in and out bed at night. A decrease in time in bed at night is visible from the biodynamic lighting condition to the normal lighting condition and an increase again when the biodynamic lighting condition returns. An increase of minutes out of bed at night is visible from the biodynamic lighting condition to the normal lighting condition and a decrease again when the biodynamic lighting condition returns. In participant 2 the effect is reversed because as this participant starts in the normal lighting condition. The same effect, however very small, is visible in the time participant 1 spends in and out bed during daytime. Participant 2 shows no difference in

time in and out of bed during daytime. Participant 3 shows only positive effects on bed leaves and napping and no positive effects on duration in and out of bed.

Figure 13. Results of participant 1 that completed three conditions (A1 (biodynamic lighting) B1 (no exposure) A2 (biodynamic lighting)

Figure 14. Results of participant 2 that completed three conditions (B1 (no exposure) A2 (biodynamic lighting) B2 (no exposure)

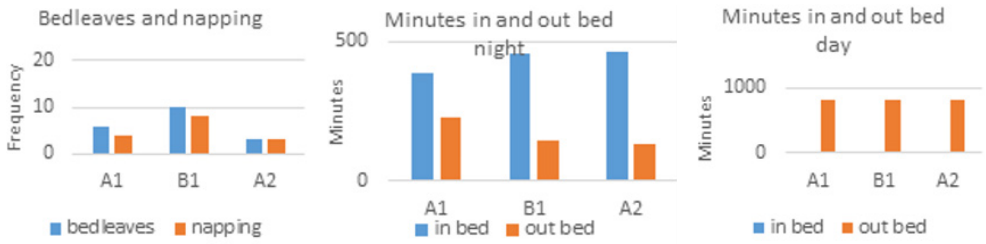


Figure 15. Results of participant 3 that completed three conditions (A1 (biodynamic lighting) B1 (no exposure) A2 (biodynamic lighting)

2.3.4 Medication

All participants used medication at start (i.e. antipsychotic medication, sedative medication, antidepressant medication, melatonin, vitamin D, and pain medication). The medication use and dosage intake was registered at the beginning and end of participation in the study. In nine participants the medication did not change during the study. In two participants antipsychotic medication was removed at the end of the normal lighting condition. In one participant sedative medication was removed at the end of the normal lighting condition and in one participant antidepressant medication was added at the end of the normal lighting condition.

2.4 DISCUSSION

The present study found positive effects of a fixed biodynamic lighting programme resembling a daylight curve on the sleeping pattern of 13 patients with dementia admitted in a clinical ward of a psychiatric hospital.

In this study three weeks of exposure to biodynamic lighting decreased the mean frequency of bed leave moments during the night from 11 to 5 times with a large effect size of 0.610. The mean frequency of daytime napping decreases from 16 naps a day to 7 naps a day. Positive effects were also found on the duration in and out bed during the night. The time in bed during the night increased 77 minutes and the time out of bed during the night decreased 76 minutes. This indicates that people are more active during the day improving their circadian rhythm.

These results are consistent with the conclusion of a review study of White et al. (2013) including 18 cited articles of RCT-studies that dynamic lighting interventions may mitigate symptoms of circadian disruption in older people living in senior living environments.

A recent study of Giménez et al. (2017) showed that in 196 hospitalised patients the objective sleep improved after five days of exposure to dynamic lighting. The sleeping duration at night

increases by 30 minutes. This is consistent with our finding that after 21 days of exposure the sleeping duration at night increases with 77 minutes.

It should further be noted that most previous studies did not specifically examine the biodynamic aspect of lighting. Previous studies, like the study from Riemersma-van der Lek (2008) demonstrated the positive effects of the exposure to vertical bright light on the sleeping pattern of people with dementia.

In our study one participant even completed six conditions and showed positive effects in the first four conditions. In the last condition the effect is not reconfirmed. A possible explanation is that at that moment this participant was told that a transition to a care home was needed. It is well known that older people with dementia react to stress with more problem behaviour such as restlessness and nightly bed wandering due to declining coping skills (2012). Taken together, the results of this study indicate that it is possible to improve the sleeping pattern in people with dementia by exposure to biodynamic lighting. It is important to note that we used biodynamic floor lamps that are suitable for home use.

Some important methodological limitations should be considered in interpreting the present results. First, the study design included a within subjects design. This design is chosen to control for most of the possible nonspecific treatment effects. But not every non-specific effect can be controlled for (like for instance seasonal impact). In addition, a significant difference between the amount of lux in both conditions ($p<0.001$) can be seen, the exact amount of lux a specific participant received, has not been measured. A personalised lighting measurement device placed close to the eye of the participant could approach this more closely. Furthermore, the sample of this study is small mainly due to the fact that it is a vulnerable group (older people with dementia in a crisis situation) to participate in long-term (max 6 weeks if they want to succeed in both conditions) research. Another limitation is the used duration of three weeks for each condition. Experienced light researchers such as Figueiro et al. (2014) used 4 weeks to reset the biological clock. However, we were able to find significant results in three weeks. Other researchers were able to find positive results in even 2 weeks (Sekiguchi et al., 2017). Furthermore, a wash-in or wash-out effect of the biodynamic lighting condition is not completely excludable. However, it is not likely as in four participants that completed more than two conditions, the effect of the biodynamic lighting is reversible.

Sleeping patterns were measured by a sensored mattress in the bed. Participants possibly also napped in a chair in the common room. These naps were not registered. Still, we can assume that these naps in a chair are comparable in frequency and time in both conditions and despite these improvements in sleeping pattern are shown in the biodynamic lighting condition(s).

Medication is often used in psychiatric hospitals. Only four single medication changes were registered in this study. No conclusions can be drawn from these medication changes, due to the often long insertion time of these types of medication (i.e. antipsychotic and antidepressant medication). Medication may have an impact on the sleeping pattern (2015), but due to the study design, the offered "treatment as usual" and the inclusion criteria, we may assume our study group is an accurate reflection of the general population.

2.4.1 Conclusions

In conclusion, the results of this study are promising to improve the sleeping pattern in people with dementia by exposure to biodynamic lighting. It supports the premise that biodynamic lighting could be a possible (early) intervention for people with dementia in at home situations. In at home situations biodynamic lighting could also result in less disturbances during the night for the (informal) caregivers. This night-time behaviour is one of the symptoms which causes a reason for the transition to a more controlled environment because of the impact on the primary caregiver (Figueiro et al., 2014; Molony, 2017).

Further research in this area is certainly needed. First of all, the current intervention effects have to be replicated in studies that control for possible nonspecific treatment effects and expectancy effects. Future studies should explore the specific contribution of the duration of the exposure and the exact received amount of lux per participant. Future research is also needed to reveal which patients with dementia respond best to this type of intervention and light program. Finally, it could be a potentially valuable direction for future studies to investigate the exact effects of biodynamic lighting on other symptoms of dementia, like attention, concentration and behaviour. Given the present effects on the sleeping pattern, positive effects might possibly also be expected in other areas.

In closing, the present findings obviously have some important implications for clinical practice. Biodynamic lighting interventions directed at improving circadian functioning might be a valuable addition to more traditional interventions, like pharmacotherapy. Based on the current results, biodynamic lighting interventions suitable for home use should be considered a promising intervention to support circadian functioning in patients with dementia living at home, particularly for patients with sleeping disturbances.

Highlights

- This study is one of the first to examine the effectiveness of biodynamic lighting suitable for home use in people with dementia admitted in a psychiatric hospital.
- Clear effects of biodynamic lighting were found on the frequency and duration of night-time bed wandering and daytime napping.
- The findings support the premise that biodynamic lighting could be a promising non-pharmacological intervention for people with dementia who still live at home.

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CHAPTER 3

EXPOSING PEOPLE WITH DEMENTIA TO BIODYNAMIC LIGHT

THE IMPACT OF BIODYNAMIC LIGHT ON NEUROPSYCHIATRIC SYMPTOMS

E.E. VAN LIESHOUT - VAN DAL
L.J.A.E SNAPHAAN
N. ARKINK
I.M.B. BONGERS

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ABSTRACT

The increase of neuropsychiatric symptoms in people with dementia count for 46% of the transit to more controlled environments. Medication to repress these symptoms is widely used, but the side effects are significant, and the effect at start is not predictable. Research that aims at non-pharmacological interventions is important. One of the promising non-pharmacological interventions is lighting. In this study the effectiveness of dynamic lighting, lighting with variable intensity and correlated colour temperature, on neuropsychiatric symptoms in older people with dementia is studied. It was hypothesised that the exposure to dynamic lighting would decrease the amount and/or the severity of the neuropsychiatric symptoms. A dynamic lighting innovation designed to stimulate a regular and healthy circadian rhythm was installed in the common area of a clinical setting. Two conditions of 21 days with and 21 days without exposure to dynamic lighting were monitored. After each condition, measures of presence, severity of symptoms and emotional impact were collected using the NeuroPsychiatric Inventory-Questionnaire (NPI-Q). Eighteen participants were included in the research and completed a condition with and without exposure to dynamic lighting. Per respondent the total index of severity of neuropsychiatric symptoms was lower after exposure. Also, on a group level a tendency ($p=.187$) was found for decreasing the total index of severity of the neuropsychiatric symptoms in the condition that received dynamic lighting. Significance was only found in the severity scores on the symptom disinhibited behaviour ($p=.01$). A dynamic lighting intervention can be used to decrease the severity of neuropsychiatric symptoms, more specific disinhibited behaviour. This is important because disinhibited behaviour is related to a disturbed circadian rhythm, is distressing for caregivers and can accelerate the process leading to institutionalisation. The findings in this study implicate the importance of future research on the possibilities of dynamic lighting in dementia.

3.1 BACKGROUND

Dementia is a common mental disorder diagnosed in (mostly) older individuals. It causes deficits in cognitive, behavioural and social functioning (Ramkisoensing & Meijer, 2015). The number of people living with dementia worldwide is currently estimated at 35.6 million. This number will be doubled by 2030. Dementia is the leading psychiatric condition for people over 60 (WHO, 2017). It is of great importance that older people with dementia stay as healthy and vital as possible so that their quality of life remains high. The costs of dementia care are high. In 2018, the Alzheimer's Association estimated the lifetime cost of Alzheimer's and dementia care at 341,840 US dollars per person. Admittance in a nursing home has a lot of impact on the older people and their informal caregivers. Several studies find that neuropsychiatric symptoms are the main determinant of informal caregiver strain and reported quality of life (Hongisto & Hallikainen, 2018) and hereby an important reason for transition of people with dementia to a more controlled environment. The reasons for institutionalisation are the need for more skilled care (65%), informal caregiver strain (49%) and neuropsychiatric symptoms (46%) (Buhr, Kuchibhatla, Clipp, 2006). Dementia can disturb the circadian rhythm even more than in normal ageing and it is aggravated by a lack of exposure to daylight. Due to a disturbed circadian rhythm, some neuropsychiatric symptoms intensify in the evening and night. Just then when the informal caregiver needs rest, leading to high distress on their part (Molony, 2017).

The cardinal symptoms of neuropsychiatric domains are delusions, hallucinations, agitation/aggression, depression/dysphoria, anxiety, elation/euphoria, apathy/indifference, disinhibition, irritability/lability, motor disturbance, nighttime behaviour, appetite/eating. (Cummings, 1994). In The Netherlands 80% of the people with dementia have one or more neuropsychiatric symptoms (Zuidema, Derksen, Verhey, & Koopmans, 2007). The treatment of these symptoms[1] exists of pharmacological and/or psychosocial interventions. The use of medication increases morbidity and mortality in people with dementia and the treatment effect on the symptoms is not always that clear and predictable (Derks, 2014). Therefore, researchers became interested in the possibilities of non-pharmacological interventions such as light.

In a systematic review by Forbes and colleagues (2014) the positive effects of light therapy on cognition, daily functioning, sleep, agitation and neuropsychiatric symptoms in people with dementia is described. The systematic review by Forbes has also been criticised by Aarts et al. (2016) and Van Hoof et al. (2010). The methodological quality of the reviewed studies is poor. An adequate description of the used light therapy method is not described. Figueiro et al. (2014) studied a small sample but also found positive effects of light on circadian rhythm, agitation and depression in dementia. Research performed by Figueiro et al. (2015), Figueiro et al. (2014) and Figueiro, Plitnick & Rea (2016) showed that the circadian rhythm, the sleeping pattern and nightly activity improved by employment of a light intensity level of 400-1000 lux and

short wavelength (bluish) light. These researchers all used a constant light intensity (lux) and Correlated Colour Temperature (CCT). Dynamic lighting offers an adjustable range of light intensity and correlated colour temperature (Light Technology Nederland, 2017). Dynamic lighting resembles a normal daylight curve and is intended to stimulate circadian rhythm. Due to age-related changes to the eye and a more disturbed circadian rhythm, people with dementia need more light but are more sensitive to light intensity, indirect light and the CCT. Research has shown that people with dementia in a nursing home only spend 1,6 minutes a day outside (Someren, 2000a; Someren, 2017) and that the indoor light conditions in a nursing home are not sufficient for the visual and the non-visual aspects of light (Figueiro et al., 2015). Also, neuropsychiatric symptoms tend to intensify in the evening and night. This nighttime behaviour is one of the symptoms, which causes a reason for the transition to a more controlled environment because of the impact on the primary caregiver (Figueiro et al., 2014). Thus, people with dementia, especially those living in a nursing home, could benefit highly from dynamic light input (Figueiro et al., 2015; Forbes et al., 2014). In this study, we will focus on the impact of dynamic lighting on the neuropsychiatric symptoms in people with dementia.

It has hardly been investigated whether dynamic lighting with its characteristic variation in light intensity and colour temperature can have a positive effect on neuropsychiatric symptoms in people with dementia. A recent study that did use dynamic lighting showed a significant decrease in agitated behaviour in people with dementia in a nursing home after two weeks of light exposure (Wahnschaffe et al., 2017). In the present study the impact of dynamic lighting on neuropsychiatric symptoms in people with dementia is investigated in a clinical setting. The methodology of the used lighting equipment is described. It was hypothesised that the exposure to dynamic light would decrease the amount and/or the severity of the neuropsychiatric symptoms.

3.2 MATERIALS AND METHODS

3.2.1 Participants and setting

The participants were recruited from a treatment facility for older people with neurocognitive disorders in psychiatric hospital Geestelijke Gezondheidszorg Eindhoven (GGzE) in Eindhoven. In a period of one year, lasting until January 2017 every new admitted patient was approached to participate. The inclusion criteria for the study were a primary diagnosis of dementia diagnosed by a geriatrician or psychiatrist, based on the *Diagnostic and Statistical Manual of Mental Disorders,* Fourth Edition (DSM-IV) criteria and the participants had to be identified with neuropsychiatric symptoms. The exclusion criteria were any other neurological disorder, including narcolepsy, sleep apnoea or restless legs syndrome or a serious eye disease

incompatible with light therapy, such as retinitis pigmentosa. People were also excluded if there is severe comorbidity of psychiatric disorders, like a manic episode, addiction or severe aggression in a psychotic episode, or if they were physically disabled and cannot leave their bed by themselves. No restrictions were made for medication use. In the absence of a legal obligation for medical ethics review, independent judgement was provided on the protection of patients' rights by conformity to the letter and rationale of the applicable laws and research practice. All study materials and procedures were approved, and ethical approval was given, by the internal scientific review committee of mental health care institution, GGzE, Eindhoven, The Netherlands (jvdp.2015002.gw). Informed consent was obtained from participant family members after full explanation of the procedures, in accordance with the Declaration of Helsinki (World Medical Association, 2017).

3.2.2 Design and intervention

The study was performed using a quantitative prospective quasi-experimental crossover design. After 21 days of exposure (condition A) the dynamic lighting lamps were removed from the common area and the group receives the regular lighting condition (condition B) during the next 21 days. Depending on the date of admittance subjects started their condition with or without exposure. The first two weeks of the condition were marked as a washout period to minimise carry-over effects (Bouter et al., 2010).

The Sparckel lamp, type Bright Brenda (Sparckel, 2018) is used in this study as lighting armature. Three lamps were placed in the common room of the ward. Participants spend most of their time in this common area. In this room they eat all their meals, play games, read, watch television, listen to music and receive visitors. In this dynamic lighting, the illuminance level and the correlated colour temperature are combined in the right proportion and varied throughout the whole day from 7:30 am to 10:30 pm resembling a daylight curve. All these aspects are accounted for in the designation of the Sparckel lamp, type Bright Brenda. This lamp has been developed after extensive research in a co-production with lighting specialists and users. A fixed day curve programme was installed and used in our study. Figure 1 illustrates the situation in a clinical ward of GGzE and figure 2 shows the floorplan of the used common room with the location of the three biodynamic lighting armatures.

Figure 1. Patient exposed to dynamic lighting

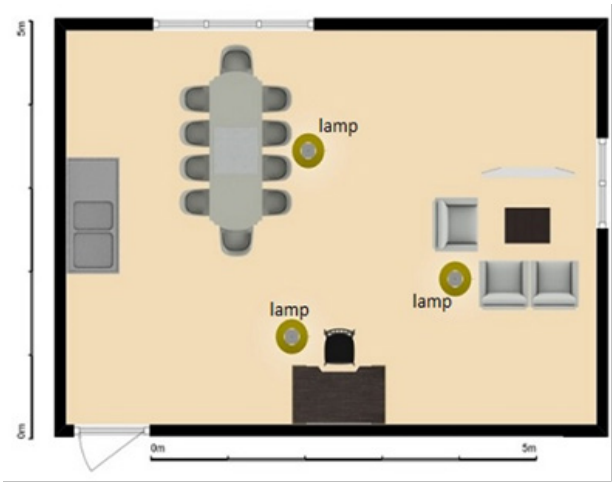

Figure 2. Floorplan of the common room

One lamp can produce up to 7500 lumen, five times more than usual in an office or living room. It also produces a CCT of 2700-6500 Kelvin (indirect-direct) and the spectrum of the biodynamic lighting simulates a regular daylight curve by following this curve in light colour and intensity. There is no risk of blue light hazard and no exposure to UV-radiance. Other important measurement data like the Colour Rendering Index and the Melanopic Effect Factor are shown in table 1.

Table 1. Measurement data of one Sparckel lamp, type Bright Brenda

Parameter	Lamp measurement	Remark
Colour temperature	4847 K 4750 K	Direct light Indirect light
Light intensity	1984.2 cd	0,1 m distance
Colour Rendering Index	87	CRI_Ra
S/P ratio	2.0	1m distance
Melanopic Effect Factor	0.682	According to standard DIN SPEC 5031-100:2015-08
Light spectrum	465-480 Nm	(equivalent) Melanopic lux
Luminous Flux	6818 lm	1 m distance
Blue light hazard risk group	0	No risk

Note: Olino Measurement Report Vitaal Licht. Retrieved from Olino website www.olino.org/private/129719/fb18f324120d03e4952d5dba8182fad0/2017.

A close-up from the topside and screen of the lamp is shown in figure 3. The topside of the lamp produces indirect light and contains 12 high power leds producing a maximum of 3 W per piece. It consists of 4 lights producing 6500K, 4 lights producing 2700K and 4 lights producing 1800K. The bottom side produces direct light and contains 196 medium power leds producing a maximum of 0.3 W per piece. It consists of 98 lights producing 6500K, 49 lights producing 2700K and 49 lights producing 1800K.

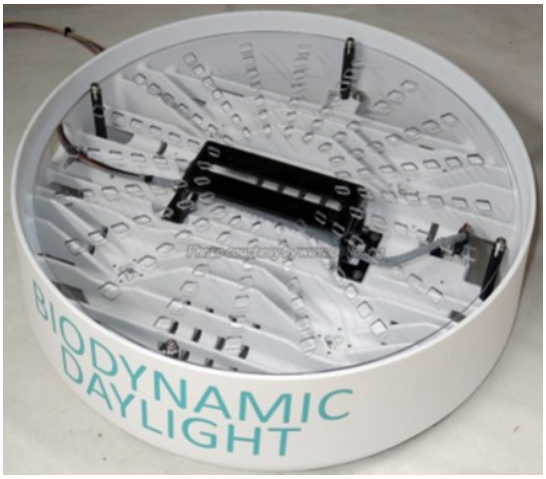

Figure 3. Topside of the lamp

Because of the sensitivity of the ageing eye, we dimmed the exposure to 75%, to increase the comfort of the older people. During the day the participants gradually received light intensity from 600 lux at 8 am, 1100 lux from 10 am until 2 pm and 600 lux at 5 pm. During the day the CCT is around 6500 Kelvin, bluish light. During the evening, the CCT is warm, around 1800 Kelvin. Figure 5 shows the power spectrum, the sensitivity curves and resulting night and day spectra at 1 m distance.

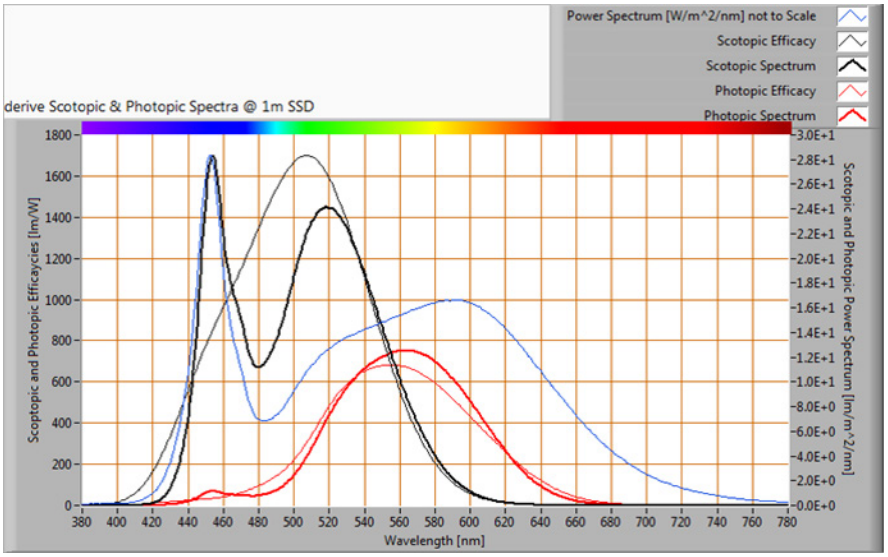

Figure 4. Power spectrum, sensitivity curves and resulting night and day spectra (1 m distance)

In order to have objective measurements of the received amount of lighting by the participants, lighting measures were collected. In each condition, the amount of lux was measured manually at least three times a week at three fixed locations in the common room at three fixed moments a day (9:00 AM, 1:00 PM and 5:00 PM). Vertical measurements were obtained at eye level because they approach the real-life situation of light collected by the ganglion cells in the eye the most. The lighting measurements were collected with a Voltcraft MS-200LED-luxmeter. Most people were exposed to dynamic lighting from 10 am to 1 pm and from 3 pm to 6 pm.

3.2.3 Measurements

When a condition of 21 days with or without exposure to dynamic lighting was finalised, the neuropsychiatric symptoms of each participant were measured with a standardised questionnaire, the NeuroPsychiatric Inventory Questionnaire (NPI-Q) by the primary formal personal caregiver of each participant (Kaufer & Cummings, 2000). The NeuroPsychiatric Inventory-Questionnaire is a standardised 12-item tool designed to rate the presence of symptoms (present or absent), the severity of the present symptoms (3-point scale) and the caregiver distress of these symptoms (5-point scale) by the primary formal caregiver. A higher score on the NPI-Q is associated with a greater severity of symptoms and greater impact of the symptom manifestation on caregivers (Kat., 2009). The NPI-Q was recently used in a 3-year longitudinal study of 514 patients to confirm the association between dementia severity and neuropsychiatric symptoms (Brodaty et al., 2015). NPI-Q were completed for all participants in both conditions.

Medication dosage and use were monitored during the study by checking the pharmacotherapy data in the electronic patient files by start and end of the participation in the study.

3.2.4 Analyses

Prior to the study a power analysis was performed. Under the assumption of a within-subject correlation of r =0.50, 34 participants would need to be included, at a 2-sided level of less than .05, a power of 0.80 to detect a moderate effect size of 0.5. A post hoc power analysis, taking into account the smaller sample size than anticipated, yielded a power of this study of 0.52 with an effect size of 0.5 (Ai-therapy Statistics). Data were analysed using SPSS, version 19 (Baarda, Van Dijkum, & De Goede, 2014). The sum scores in condition A and B were compared at symptom level, group level and participant level.

3.3 RESULTS

From January 2016 to January 2017 sixty-one older people with dementia were admitted to psychiatric hospital GGzE in Eindhoven, The Netherlands. Two people did not sign the informed consent, nineteen people could not be included because of severe comorbidity of psychiatric disorders (i.e. manic episode, psychotic episode, aggression caused by detox of substance abuse) and/or physical complications (i.e. wheelchair dependence, kidney dialysis) and twenty-two people did not complete two conditions (i.e. transition, discharge, death). Eighteen participants were included in this study (nine men, nine women; mean age was 76.4 ± 11.7 years) and completed two conditions. Four participants completed four conditions in an ABAB-design. All participants used medication at start (i.e. antipsychotic medication, antidepressant medication, melatonin, vitamin D, pain medication). In four participants, medication was changed during the study. Two participants received no antipsychotic medication during the condition with exposure and did in the condition without exposure. One participant received no sedating medication in the condition with exposure and did in the condition without exposure. One participant received no antidepressant medication in the exposure condition and did in the condition without exposure.

For a description of the included study population see Table 2. Ten participants started with exposure to dynamic lighting (condition A) and eight participants started with the normal daylight condition (condition B).

The mean amount of lux in the 'dynamic lighting' condition was 1150 lx ± 560 lx with a minimum of 390 lx and a maximum of 1900 lx. The mean amount of lux in the 'normal lighting' condition was 390 lx ± 280 lx with a minimum of 60 lx and a maximum of 900 lx. A two-tailed paired t-test did show a significant difference between the amount of lux in both conditions ($p<0.001$).

Table 2. Description of study population

	n=18	
Age	76,4 (11.7)	
Sex		
Male	9 (50%)	
Female	9 (50%)	
Dementia Type		
Alzheimer's Disease	6 (33%)	
Frontotemporal dementia	1 (5.5%)	
Dementia due to substance abuse	1 (5.5%)	
Dementia NOS	10 (55%)	
Medication	**Start**	**End**
Typical antipsychotics	14 (67%)	8 (44%)
Atypical antipsychotics	3 (16.5%)	6 (33%)
Sedatives/ Benzodiazepines	9 (50%)	9 (50%)
Pain medication	7 (38.5%)	6 (33%)
Antidepressants	4 (22%)	5 (27.5%)
Other medication (e.g. vitamin D)	13 (71.5%)	13 (71.5%)

SD or percentages are shown in brackets

Severity of neuropsychiatric symptoms

As shown in Table 3, a significant difference was found for only one neuropsychiatric symptom. For the symptom disinhibited behaviour a significant decrease was revealed between exposure and no exposure to dynamic lighting (P=.01). The data were not normally equated. Therefore, the Wilcoxon signed rank test is used to compare the data.

Table 3. Scores on severity of symptoms in condition A (exposure) and condition B (no exposure).

Neuropsychiatric symptoms	Condition A n=18 mean (sd)	Condition B n=18 mean (sd)	sign. (p)	Participants (n) Condition A compared to B increased	decreased	equal
1. Delusions	1,00 (1,00)	1,44 (1,29)	0,11	2	8	8
2. Hallucinations	0,56 (1,04)	0,67 (1,19)	0,49	1	4	13
3. Agitation/aggression	1,11 (1,08)	1,33 (0,98)	0,36	5	6	7
4. Depression/dysphoria	1,17 (0,92)	0,78 (0,81)	0,24	8	3	7
5. Anxiety	1,11 (1,23)	0,72 (1,23)	0,25	7	2	9
6. Euphoria/elation	0,28 (0,75)	0,39 (0,70)	0,48	2	3	13
7. Apathy/indifference	0,50 (0,79)	0,50 (0,92)	1,00	3	2	13
8. Disinhibited behaviour	0,33 (0,77)	1,22 (1,26)	0,01*	1	11	6
9. Irritability/lability	0,83 (1,10)	1,22 (1,17)	0,23	2	8	8
10. Aberrant motor	0,39 (0,85)	0,11 (0,32)	0,16	4	1	13
11. Nighttime behaviour	0,72 (1,13)	1,17 (0,99)	0,21	4	9	5
12. Appetite/eating	0,17 (0,51)	0,17 (0,71)	1,00	1	1	16

* indicates a significant difference at severity of symptoms between condition A (exposure to biodynamic light) and condition B (no exposure)

The mean total score in the exposure condition is 8.1 (SD=6.4) and in no exposure condition 9.6 (SD=6.0) (P=.289). Visual inspection of the variables shows that none of the scores was normally equated. The non-parametric Wilcoxon signed rank test was used to analyse the data. At group level a comparison is made in total score with and without exposure to dynamic lighting.

The total scores of severity of symptoms at individual level in both conditions is shown in Figure 5. The first eight participants started in condition B (no exposure). In five participants the total score of severity decreased in condition A (exposure) and in three participants the score increased in condition A. Ten participants started in condition A (exposure) and in five participants the total score of severity of symptoms increased in condition B (no exposure), decreased in three participants and stayed equal in two participants.

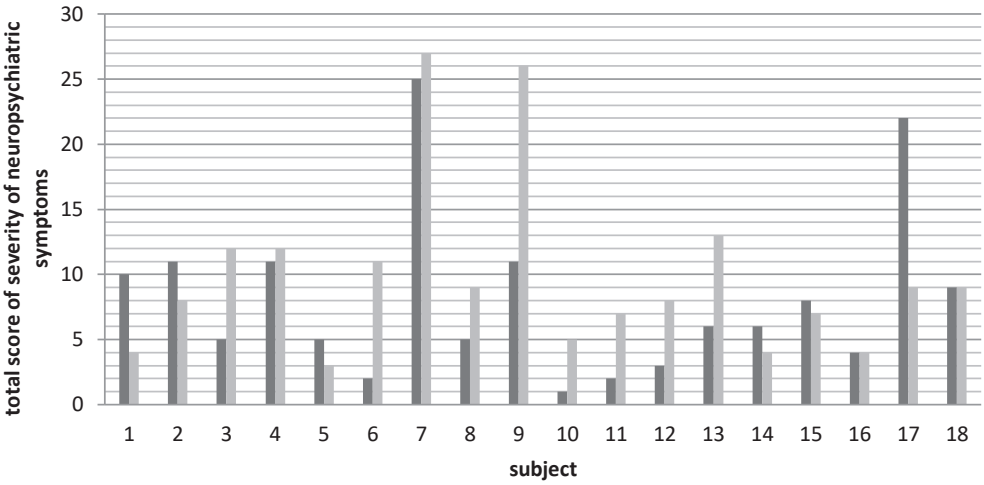

Figure 5. Total score of severity of symptoms per participant in condition A (black) and B (grey).

The total score of (formal) caregiver distress was also compared. There was a decrease in scores on emotional impact on caregivers reported by caregivers in 11 participants in condition A. In one participant the emotional impact scores reported by the caregiver were equal in both conditions. In 6 participants the caregivers reported higher emotional impact scores in condition A compared to condition B.

In condition A the mean total score of caregiver distress is 8.89 (SD=7.9) and in condition B 11.00 (SD=6.18). A Wilcoxon signed rank test was performed and no significance was found (p=.087).

Four participants completed two A and two B conditions in an ABAB-design. Visual analysis of all participants in Figure 3 show that dynamic lighting has a positive impact.

In all participants there is a positive effect of scores on severity and emotional impact of the formal caregiver compared to the previous condition. This suggests that dynamic lighting can have a positive effect on severity of symptoms and emotional impact on caregivers when exposed to this lighting for a prolonged period. The effect is reversible which indicates the positive effect is caused by the exposure to dynamic lighting. In participant 1 and 4 the effect however is not that strong. Both participants were psychically deteriorating and suffering from alcohol-induced dementia. They were both not able to return to their homes and were admitted in a nursing home.

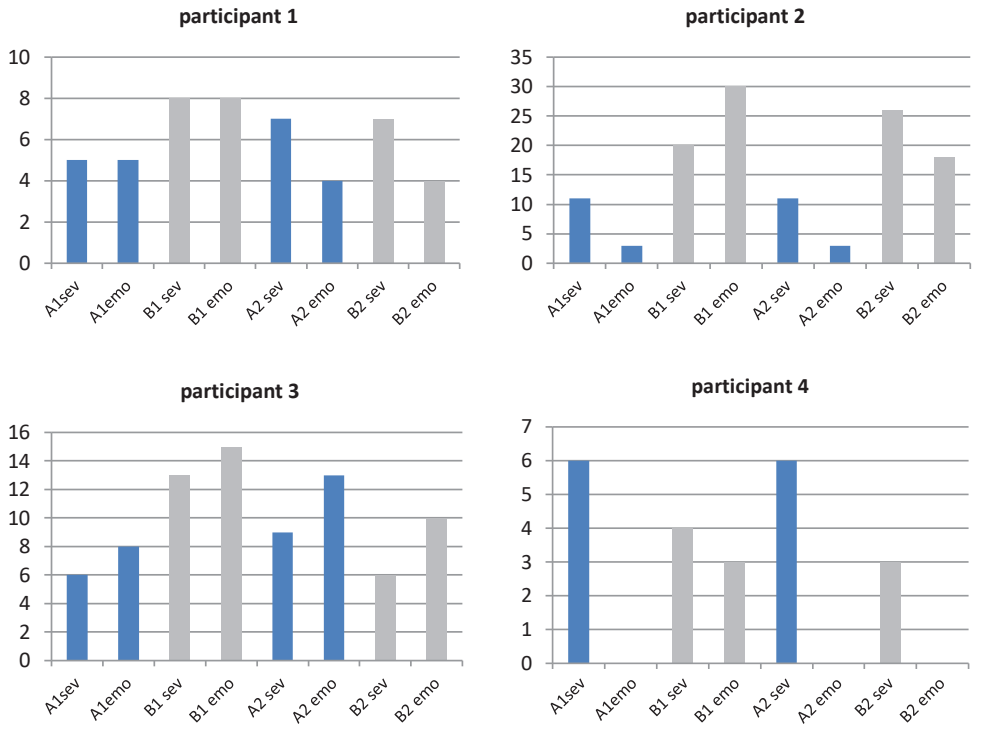

Figure 6. Results of four participants that completed an ABAB-condition
Note: sev = severity of symptoms, emo = emotional impact on caregiver

3.4 DISCUSSION

The present study set out to investigate the effects of a dynamic lighting intervention on neuropsychiatric symptoms in people with dementia admitted to a psychiatric hospital during January 2016-January 2017. It was hypothesised that exposure to dynamic lighting during the whole day and evening (7:00-23:00) with an average of 3-6 hours of exposure time a day would have a more positive impact on the measures of severity of neuropsychiatric symptoms at clients and scores of emotional impact on formal caregivers than the normal lighting conditions in the common room of the hospital. Eighteen participants primarily diagnosed with dementia with a mean age of 76 years were included in this study. The effect of exposure to dynamic lighting has been measured on different levels (symptom, individual and group). Information and selection bias were minimalized by questioning mostly the same formal caregiver per participant by one and the same investigator. The internal validity was ensured by collecting all data of the NPI-Q and the data of the electronic patient files and registered in SPSS.19. Co-researchers independently controlled all the data and analyses. By placing three

Sparckel lamps in the common area of the ward the internal validity was also ensured as people are exposed to dynamic lighting at any place in the common area.

The present results showed that a 21-day exposure to dynamic lighting decreased the total score of severity in seven (delusions, hallucinations, agitation/aggression, euphoria/elation, disinhibited behaviour, irritability/lability and nighttime behaviour) of the 12 symptoms. Only at the symptom disinhibited behaviour a significant difference was revealed (P=.01). This finding is consistent with recent research of Wahnschaffe et al. (2017) who found that dynamic lighting in a nursing home significantly reduced scores on the Cohen Mansfield Agitation Index (CMAI). The CMAI includes several symptoms of disinhibited behaviour. Another study of Brodaty et al (2015) which followed the prevalence and course of neuropsychiatric symptoms on the NPI-Q in dementia over 3 years, found that overall levels of neuropsychiatric symptoms increased over 3 years, in particular delusions, hallucinations, agitation, anxiety, apathy, disinhibition, irritability and aberrant motor behaviour significantly increased. Actually, several of these symptoms (delusions, hallucinations, agitation, disinhibited behaviour and irritability) even decreased a very important finding in our study. Medication was monitored and there was no medication prescribed influencing this behaviour. Lighting can stimulate the circadian rhythm and hereby might have a positive impact on disinhibited behaviour because people sleep better, are less tired and can regulate their behaviour better.

Ten participants out of 18 reported a decrease in the total score of severity of symptoms based on the exposure to dynamic lighting. Although we did not reach significance on a group level, the same trend was found on an individual level. Other factors on the ward also influence neuropsychiatric symptoms in participants and might have contributed in not reaching significance, like a new admittance, the decease of a patient and severe disrupting behavior like suicidal gestures or a patient suffering from psychosis.

In three participants who started in the exposure condition, the total score of severity of symptoms increased compared with the no exposure condition. This is the opposite result of our hypothesis. Possible reasons for these findings could be that according to Zuidema (2007) neuropsychiatric symptoms increase because of the progressive state of dementia. On the other hand, we also found participants who ended in the exposure condition the total score of severity of symptoms decreased. It could be that because of the exposure to Sparckel lighting, people become more active and notice their limitations in daily life more. This assumption could also be seen in our results because the largest difference was found in symptoms of delusions, disinhibited behaviour and nighttime behaviour. Another possible explanation for the increase of severity of symptoms during the exposure condition at the start of the study could be the emotional impact and consequences of an admittance in a hospital.

Four participants completed two full conditions as in an ABAB-phase design. In all conditions, there was a positive effect on scores of severity of symptoms and emotional impact on caregivers compared to the previous condition. This effect was reversible in three of the four participants. In the exposure condition the neuropsychiatric symptoms and the emotional impact on the formal caregivers decreased, then it increases during the no exposure condition, it decreases again in the exposure condition. This suggests a positive impact of dynamic lighting when participants are exposed for a prolonged period. The participant that shows no reversible effect was suffering from increasing somatic complaints and was admitted in a nursing home.

The present study also has some limitations. The exposure to dynamic lighting reduces neuropsychiatric symptoms indicating short-term effects from higher daily light exposure. The found effect however might not be strictly due to the dynamism of the used lighting armatures. The found higher lighting levels, the colour temperature or a combination thereof can also obtain results. This study should be replicated using a larger sample size to increase the power of the study and using a longer treatment duration to determine if long-term exposure could significantly reduce neuropsychiatric symptoms in people with dementia, and therefore reduce formal caregiver distress. Further investigation is also needed before results can be extrapolated to at home situations. It is possible that people with mild dementia would benefit more from light treatment as their SupraChiasmatic Nuclei (SCN) is likely to be less degenerated. Participants in this study had severe dementia. Furthermore, formal caregivers may have known the purpose of the intervention and answered accordingly, however this is unlikely because they were unfamiliar with the questionnaire and their responses did not always favour the intervention condition. The choice of using proxy-data instead of self-report data stemmed from the fact that all participants were diagnosed with dementia.

Another limitation is that there was no baseline measurement. Several variables could have influenced the symptoms during the treatment duration. To minimise these influences, the conditions should be repeated several times within the subjects to be able to make conclusions about implications (Bouter et al., 2010).

The positive effect of light is also found in previous research. A recent systematic review of Mitolo et al. (2018) on the effects of light treatment describe some studies that show some effect of bright light therapy on the reduction of agitation in people with dementia (Burns et al., 2009; Lovell et al., 1995; Mishima et al., 1994). Figueiro et al. has shown the positive effect of light exposure in several studies (2014, 2015 & 2016). They found an increase of sleep duration and a decrease of symptoms of depression and agitation with exposure to dynamic lighting interventions. Shirani and Louis (2009) concluded positive effects in a study on sleep, depression and dementia with exposure to 5000 lux one hour per day for

several weeks. Onega et al. (2016) showed that bright light exposure was associated with significant improvement in depression and agitation in people with dementia. To improve the methodological quality of future light studies Aarts et al. (2016) and Van Hoof et al. (2010) suggest a multidisciplinary approach and a combination of the efforts of a medical/biological researcher and a light engineer. There were three lamps in the common ward producing a maximum of 5625 lux. The correlated colour temperature also varied. In the morning bright-bluish light was produced and in the evening warm red light (2700-6500 Kelvin). Participants were at least 180-360 minutes a day exposed to dynamic lighting, because of their daily activities. The aim of this study was to investigate a non-pharmacological intervention that can reduce the neuropsychiatric symptoms in people with dementia. Medication use and doses intake were monitored during the study. The present study showed that dynamic lighting exposure for three weeks in a geriatric ward of a psychiatric hospital significantly decreases disinhibited behaviour. This finding is consistent with the study of Wahnschaffe et al. (2017) and implies dynamic lighting is a promising intervention in influencing disinhibited behaviour in people with dementia. According to the review study of Sink, Holden and Yaffe (2005) primary treatment of neuropsychiatric symptoms consists of non-pharmacological interventions, because the effect of medication use is not clear at start and because of the side effects. The clinical relevance of the exposure to dynamic lighting as non-pharmacological intervention is confirmed in this study. The Sparckel lamp might even be suitable for home use and hereby reduce the informal caregiver distress that is one of the main reasons for transition of older people with dementia to more controlled environments.

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CHAPTER 4

TESTING A SINGLE-CASE EXPERIMENTAL DESIGN TO STUDY DYNAMIC LIGHT EXPOSURE IN PEOPLE WITH DEMENTIA LIVING AT HOME

E.E. VAN LIESHOUT - VAN DAL
L.J.A.E SNAPHAAN
S. BOUWMEESTER
Y.A.W.D. DE KORT
I.M.B. BONGERS

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HTTPS://DOI.ORG/10.3390/APP112110221

ABSTRACT

Most people with dementia live at home supported by informal caregivers, but disturbed sleep patterns may induce a heavy burden of care. The beneficial effects of bright light on their sleep, health, and well-being have been demonstrated in clinical settings, but not in a home situation. We evaluated a dynamic lighting system in a real-life longitudinal single-case experimental design (SCED) with people with dementia living at home. Eleven people with dementia and their informal caregivers were included in this study with four 4-week periods of alternating exposure and no exposure in an introduction–withdrawal setup (ABAB). Objective light exposure data were collected and analysed. The used study design seems applicable for this population and suitable for home use. Participant dropout did occur, but was due to health conditions rather than participant burden. The lighting system led to more light in the homes of the participants, as well as to higher actual individual light exposures, although the latter increased only moderately and not consistently across all participants, seasons, and times of day. The participants appreciated the lighting system even after 6 months. We reflect on individual differences, seasonal and daypart influences, and differential light effects. Recommendations and lessons learned are discussed.

4.1 INTRODUCTION

Due to age-related changes in the eye, ageing comes with an increasing demand for higher light levels that support good vision and help synchronise one's biological clock (Boyce, 2003; Figueiro et al., 2017; Shikder et al., 2012). Extra bright light is needed for daily activities and to prevent people from falling. In addition, exposure to daylight or artificial light at the right time of day is a strong and crucial cue for synchronising the biological clock. This biological clock plays an important role in the timing and coordination of physiological and psychological processes with a circadian (24 h) rhythm, including our sleep–wake rhythm and well-being. Dementia can disturb the biological clock more strongly compared with healthy ageing, which is especially problematic during the darker seasons, such as fall and winter (Wahl et al., 2019). This can result in the manifestation of symptoms, such as nightly wandering, restlessness, and agitation (Abbott, 2003; Harper et al., 2005). These symptoms cause a high burden for informal caregivers (e.g., spouses, children, and relatives) and are the main reasons for institutionalisation. In fact, the prevalence of these symptoms increases the chances of institutionalisation by 10 times (Bantry White & Montgomery, 2016; Hatfield et al., 2004). Because of their ageing eyes and their neural deterioration, persons with dementia would substantially benefit from extra bright light exposure in their home environment. Daylight is a natural source of well-timed and very bright light, yet indoor daylight entrance is limited and persons with dementia tend to spend less time outside than people without dementia (Skene & Swaab, 2003. Spending significantly less time outside causes further understimulation of their biological clock, and this increases the risk of loss of healthy circadian entrainment (Bantry White & Montgomery, 2016; Goudriaan et al., 2021; Hanford & Figueiro, 2013; Scott et al., 2020; Skene & Swaab, 2003).

Daylight naturally offers contrasting light and dark conditions over the 24 h day that our biological clock requires for healthy entrainment. The exact natural light dynamics are, of course, dependent on geographical location, time of day, and season. The illuminance and spectral composition of natural light are additionally influenced by weather conditions, such as haze and overcast White et al., 2013; Aarts et al., 2018). In addition, there are indications that, depending on the time of day and the individual's affective and/or mental state, different lighting conditions across the day are needed to optimally support human functioning (Kompier et al., 2020, 2021). Particularly for persons who have older eyes, a diminished functioning of the internal clock, and who receive little direct exposure to daylight, dynamic artificial lighting that mimics the natural rhythm of night and day may stimulate physical and mental health and generate a positive experience. As the biological system is differentially sensitive to different wavelengths, dynamics in both light intensity and the light spectrum have an impact on physiological and psychological processes in the human body (Blume et al., 2019; Figueiro et al., 2012).

In recent years, the use of dynamic lighting for people with dementia has become increasingly popular, and several care facilities have purchased dynamic lighting with the intention of improving the well-being and day–night rhythm of persons with dementia. However, these lighting systems are in most cases not suitable for people with dementia still living at home, mostly due to the purchase and installation costs and practical implications, such as actual usability and the personal preferences of people with dementia and their caregivers (Fontana Gasio et al., 2003; Goudriaan et al., 2021). Moreover, older adults best appreciate a lighting intensity level around 1000 lx, and due to age-related macular degeneration, their eyes are more sensitive to direct and, therefore, indirect light; thus, lighting in which the light emitted by a source is diffusely reflected is often more appreciated (Figueiro et al., 2014, 2016). Standard light therapy boxes are therefore unsuitable for people with dementia as these boxes offer direct light of very high intensity illuminance levels (lx) and, sometimes, of high correlated colour temperature (CCT).

Previous studies have demonstrated the beneficial effects of bright or dynamic light exposure on the sleep quality cognition and well-being of persons with dementia (Gül et al., 2015; Hoof et al., 2009; Lieverse et al., 2011; Riemersma-van der Lek et al., 2008). Most studies on this subject have, however, been performed in nursing and care homes. Studies focusing on persons with dementia still living at home are extremely scarce (Figueiro et al., 2016; Nioi et al., 2017; Sloane et al., 2015). Kinnunen et al. (2017) concluded in a review article on interventions for people with dementia at home that light therapy is a promising strategy to alleviate the circadian disturbances and improve the well-being of people with dementia. It is important to note, though, that these studies used a variety of light therapy approaches and do not always report explicitly how the light doses received by the participants were measured or monitored. As Figueiro et al. (2016) concluded, it is one of the biggest future challenges to find a suitable and practical method for effectively delivering brighter daytime light to the eyes of people with dementia still living at home.

It is difficult to conduct light research on people with dementia living at home because of the heterogeneous population, living circumstances, diffuse nature of the disease, and practical objections, such as being proficient in the use of devices. In addition, to measure the effect of a lighting intervention, participants need to be followed over a long period of time. A longitudinal study design is difficult—in this population—and many variables may influence data collection. For example, a recent field investigation in an office context demonstrated that light interventions may be far less effective than hoped in terms of increasing personal light exposure, and that this effectiveness is substantially influenced by contextual and behavioural factors (Peeters et al., 2020). It is therefore essential to take into account the individual user and his or her context. The individual characteristics, living situation, and dementia stage may all play a role in the practical feasibility of implementing light innovations in a home situation.

Randomised placebo-controlled trials (RCTs) are still considered the gold standard in medical research, but naturally, they also have limitations. RCTs have strong internal validity, but their external validity often remains inadequate. The generalisation of findings outside of the study group is, by no means, always justified. There is little "real-life evidence", and the transition from group evidence to evidence relevant to the treatment of individuals cannot be made. There is no focus within an RCT on the influence of individual patient characteristics, and a heterogeneous group, such as patients with dementia, is hard to study properly using this design. A disadvantage of other study designs, however, is that without randomization in daily practice, it is difficult to reliably link positive effects to an intervention. In addition, researchers would like to be able to compare new interventions with existing ones.

Field studies on dementia are challenging. However, to determine what functional specifications an innovation requires to support patients with dementia and to find out in practice whether this system is experienced as effective, real-life or field studies are necessary and valuable. In several real-life studies (Bonci et al., 2020; Corrà et al., 2020; Dallery et al., 2013; Figueiro et al., 2014; Hein et al., 2017; Kieboom et al., 2019 Krasny-Pacini & Evans, 2018; Nioi et al., 2017; Peeters et al., 2020; Rasquin et al., 2007; Sekiguchi et al., 2017; Smith, 2012), caregivers of patients with dementia have pointed out the need for support. Technological systems could be a solution to the problems they encounter, such as getting lost and wandering behaviour at night due to circadian disruption. It seems that patients who are in an early stage of dementia would profit the most from these technological devices (Hein et al., 2017; Rasquin et al., 2007; Sekiguchi et al., 2017).

Therefore, in the current study a real-life single-case experimental design (SCED) was chosen in which the results were analysed by randomization testing. In doing so, a combination of the advantages of an RCT and the advantages of a real-life field study was attempted. The ecological validity of this study design is high as lessons are learned and shared in the design of a sustainable research protocol. It is necessary to evaluate whether the applied SCED and the methods of data collection and data analysis are applicable for measuring the effect of dynamic lighting on people with dementia living at home.

The current study served two primary research aims: First, we tested whether the used study protocol is applicable and feasible, and by reporting our lessons learned, we aim to provide recommendations for developing a suitable measurement protocol to investigate light interventions for home use. Second, we investigated whether people with dementia living at home would be exposed to substantially brighter light when the dynamic lighting system was present in their home compared with regular lighting. Due to various external factors, such as participants not spending a whole day sitting under a lighting system and participants going outside into daylight during the intervention condition, whether a relatively limited set of off-

the-shelf luminaires would result in a measurably different exposure is a relevant question. In addition, we explored differences in light exposure at different dayparts and assessed whether differences were moderated by season. Finally, the subjective experience of the participants on the light system was evaluated.

4.2 MATERIALS AND METHODS

4.2.1 Design

A longitudinal study was performed among people suffering from dementia living at home to measure the effectiveness of a dynamic light intervention on persons' personal light exposure. A SCED design was used (Dallery et al., 2013; Krasny-Pacini & Evans, 2018; Sekiguchi et al., 2017; Smith, 2012) to include individual differences, such as living situation, phase, and progression of dementia. The results were evaluated at both the individual and group levels.

In SCEDs, patients are followed by means of repeated measurements during a baseline and an intervention phase and, as such, provide insight into the effects of an intervention (Dallery et al., 2013; Krasny-Pacini & Evans, 2018; Smith, 2012). In this study, a repeated introduction–withdrawal $A_1B_1A_2B_2$ design was used to evaluate (1) differences in the light supply in the A_1 vs. B_1 conditions, (2) the reversal effect of the removal of the lighting system during A_2, and (3) light differences of the reintroduction during phase B_2.

If a significant difference in lighting conditions was present in the first exposure condition (A_1 vs B_1), this effect was expected again in the second exposure condition (A_2 vs. B_2), indicating a strong effect of the intervention. To minimise carry-over effects, the first 2 weeks of each condition were marked as washout and adjustment periods, and only the last week (4th week) was used for data collection (Bonci et al., 2020; Corrà et al., 2020).

4.2.2 Participants

Thirteen participants and their informal caregivers (n = 13) received information about the research project and were willing to participate. Written informed consent was obtained from all the participants and their caregivers. One couple decided to stop before data collection started, and 1 couple decided to stop on the 1st week of data collection due to changes in their health conditions (pp06). Therefore, the total sample size of this study was 11 participants. One participant, pp11, completed two of the four phases and decided not to complete the other two phases due to sudden deterioration of the condition, which required full attention. We obtained complete data of four phases of 10 participants. The participants were recruited by formal caregivers of the Innovate Dementia network (Kieboom et al., 2019) and through posts via social media and Alzheimer Café meetings in the Netherlands within the period

of September 2019 to June 2020. The study protocol was approved (23 April 2015) by the Institutional Review Board of the mental health care institute Eindhoven (GGzE) and by the Medical Ethics Committee (METC) of Noord-Brabant (29 August 2018, P1826), the Netherlands. Both participants and their informal caregivers signed a written informed consent form, in accordance with the Declaration of Helsinki (2014) and the General Data Protection Regulation (AVG; www.eugdpr.org) (as applied in 2018).

The inclusion criteria for the study were: (1) having a primary diagnosis of dementia, diagnosed by a geriatrician, neurologist, or psychiatrist, based on the criteria of the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V, 2013); (2) living in a home situation; (3) having sleeping problems based on the Neuropsychiatric Inventory Questionnaire; (4) having sufficient cognitive ability to participate in this study, a score of 24 or above on the Mini-Mental State Exam (MMSE), and being mentally competent to decide for themselves to participate ; (5) no visual disabilities or wheelchair dependence; and (6) having an actively involved informal caregiver who frequently checks the well-being of the participant. Patients were excluded from the study if any other neurological disorders or a serious eye disease, such as retinitis pigmentosa, was diagnosed, which makes light intervention incompatible.

As Table 1 shows, the study population included 11 participants (5 women and 6 men) with a mean age of 78.1 years. The mean score on the Mini-Mental State Exam (MMSE), a questionnaire to measure cognitive impairment, was 24.6. A score below 24 can indicate mild to severe cognitive impairment and possible mental incompetence to participate in the study. For 8 participants, the informal caregiver was their spouse, while for the other 3 participants, it was their daughter (in-law). The mean age of the informal caregivers was 68.2 years. Eight participants were diagnosed with Alzheimer's dementia, 2 participants with Lewy body dementia, and 1 participant with frontotemporal dementia. All the participants experienced sleeping problems.

Table 1. Participant and caregiver demographic variables at baseline (n = 11)

	Participants	Caregivers
Gender		
Male	6	3
Female	5	8
Dementia type		
Alzheimer's	8	
Lewy body	2	
Frontotemporal	1	
Relationship with participant		
Spouse		8
Daughter (in-law)		3
Mean age (SD)	78.1 (8.56)	68.2 (11.59)
Mean MMSE score (SD)	24.55 (2.3)	

4.2.3 Procedure

A transportable dynamic lighting system was used in our study, which was designed for the home setting. It consisted of three high-intensity lamps that exposed people to indirect and direct dynamic light in their own home. The lighting system roughly follows a strong daylight curve in intensity, with an extra strong contribution of shorter wavelengths in the morning and lower contribution in the evening, as this is hypothesised to optimally support a healthy circadian rhythm (e.g., CIE). We placed one lamp in the living room, one in the kitchen, and one in the bedroom of the participants. As different kinds of light may have differential effects on people, we distinguished between light intensity (lx) and correlated colour temperature (CCT; the colour appearance of white LEDs). Where full spectral data were available, we also reported the melanopic equivalent daylight intensity (EDI), given its relevance to the circadian effects of light. In addition, we explored whether there were differences in light exposure at different dayparts (morning, afternoon, and evening) in the control and test conditions. We also assessed whether differences were moderated by season: the dynamic lighting system might be more appropriate in darker seasons (i.e., fall and winter) than in seasons with more natural light as is often the case in spring and summer.

To prevent the participants from adjusting the offered lighting scenario, a timer switch was connected to all the three systems, which enabled the systems to turn on and off in a program tailored to their preferred day rhythm. The light switches on the lamps were covered so that the participants could not turn them on and off themselves. The SCED design enables the incorporation of personal preferences. Personal lighting scenarios were programmed, and the researcher installed the app on a smartphone or tablet and provided the participant

instructions on how to use the app. The participants received a wearable light sensor button that was connected to the app and needed to be placed as close to the eyes as possible, usually on the collar. Each condition lasted 4 weeks. The dynamic lighting system was removed from the home during the regular lighting condition. In the last week of every condition, the participants wore the light sensor button from the moment they woke up until the moment they went to bed. The charger of the light sensor was placed on the bedside table. Both the caregivers and participants received the instructions of the study protocol at the same time. During the study, a help desk was offered to resolve technical problems with the lighting system or light sensors. In consultation with the informal caregivers, manual control of the lighting system was disabled. The lighting system was stable and solid, and damage and destruction did not take place.

Immediately after finishing the study, the users were asked questions about their experiences in their participation and the study protocol. The subjective experiences of the people were evaluated, as their (positive) experiences will ultimately determine the usefulness of the lighting system. Six months after finishing the study, the users were asked via an evaluation form to answer questions about whether they experienced the lighting system as pleasant, disturbing, or too bright; if they believed it had had an impact on their health; and if they would recommend or purchase the system.

4.2.4 Lighting Intervention

In this study, a Waldmann VIVAA Free Visual Timing Light lamp (VTL-lamp) and a LIFX-A60 light bulb, both shown in Figure 1, were used in the dynamic lighting system. The VTL-lamps were placed in the kitchen and in the living room near those seats where the participants spent most of the daytime. The free-floor standing luminaires provided both direct and indirect lighting via the ceiling. The illuminance level and color temperature of the light varied dynamically across the day. From 7:00 a.m. onward, the light increased quite fast across 30 min to medium level, and then more slowly from 7:30 to 9:30 a.m. until its peak value. There, it remained until 3:30 p.m., when it gradually started to decline to reach 0 lx at 9:00 p.m. The CCT started high (6000 K, quite cool, bluish light) in the morning (7:00–9:00 a.m.) to boost the circadian rhythm. Then CCT gradually decreased to 4000 K (normal white light) and stayed there until 4:00 p.m. In the late afternoon and early evening, the CCT was lowered to 3000 K, and from 7:00 p.m. onward, it slowly lowered from 2500 K to 2250 K (warm yellowish light) until it was dimmed completely. The exact intensity levels depended on the exact seating position of the person, ceiling height and colouring, and shape and texture of the furniture, but were estimated as indicated in Table 2. Spectral distributions of the light varied constantly. Figure 2 visualises the spectra in the middle of each phase described in Table 2. Full stimulus specification tables and spectra are publicly available via the Open Science Framework (OSF, 2021). Measurements were taken horizontally, approximately at the lap level of a seated person, and vertically, approximately

at eye level of a seated person. Both photometric illuminance and melanopic equivalent daylight (D65) illuminance (EDI_{mel}) are reported. The first measure is most relevant to the visual system, while EDI_{mel} is more indicative of the activation of the photoreceptors that project to the biological clock. There was a low risk of blue light hazard, the Unified Glare Rating was below 16, and there was no exposure to UV radiance. The colour rendering index (Ra) was >80.

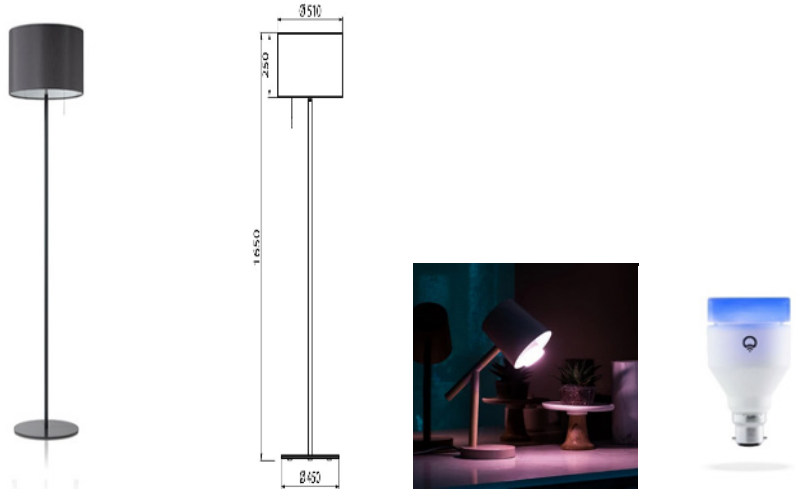

Figure 1. The used lighting system: (left) Waldmann VTL-lamp; (right) LIFX dynamic light bulb.

Table 2. Estimated illuminance and equivalent daylight (D65) illuminance (EDI) based on the task/lap and eye levels of the free-floor standing luminaire.

Phase		**Description**		**CCT**	**Task Lighting ($E_{horizontal}$ at Lap Level)**		**Personal Exposure ($E_{vertical}$ at Eye Level)**	
From	To	Intensity	Color		Illuminance (lx)	EDI_{mel} (lx)	Illuminance (lx)	EDI_{mel} (lx)
7:00 a.m.	7:30 a.m.	Fast increase	Cool white	6000 K	0–1000	0–1100	0–350	0–370
7:30 a.m.	9:30 a.m.	Slow increase	Regular white	6000–4000 K	1000–2600	1100–2300	350–850	370–770
9:30 a.m.	3:30 p.m.	Stable	Regular white	4000 K	2600	2300	850	770
3:30 p.m.	5:30 p.m.	Slow dimming	Warm white	4000–3000 K	2600–1300	1700–700	850–430	580–250
5:30 p.m.	7:30 p.m.	Very slow dimming	Warm white	3000 K	1300–650	800–300	430–220	270–100
7:30 p.m.	9:00 p.m.	Very slow dimming	Very warm white	2500–2250 K	350–0	115–0	115–0	40–0

Note: Estimates based on measurements performed in a small white room without daylight, with a spectrometer fixed at the average estimated lap position to measure horizontal task illuminance and at the estimated eye position to measure vertical illuminance. This table reports the beginning and end states of dynamic phases. Numbers have been rounded off for readability.

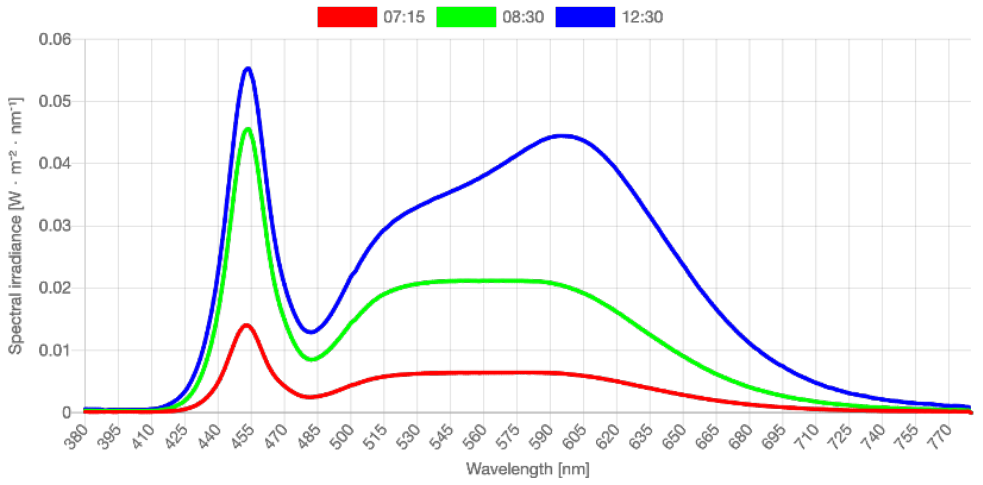

Figure 2a. Spectral distributions measured in the middle of dynamic phases as reported in Table 2: measured at 07:15 a.m., 08:30 a.m., and 12:30 p.m.

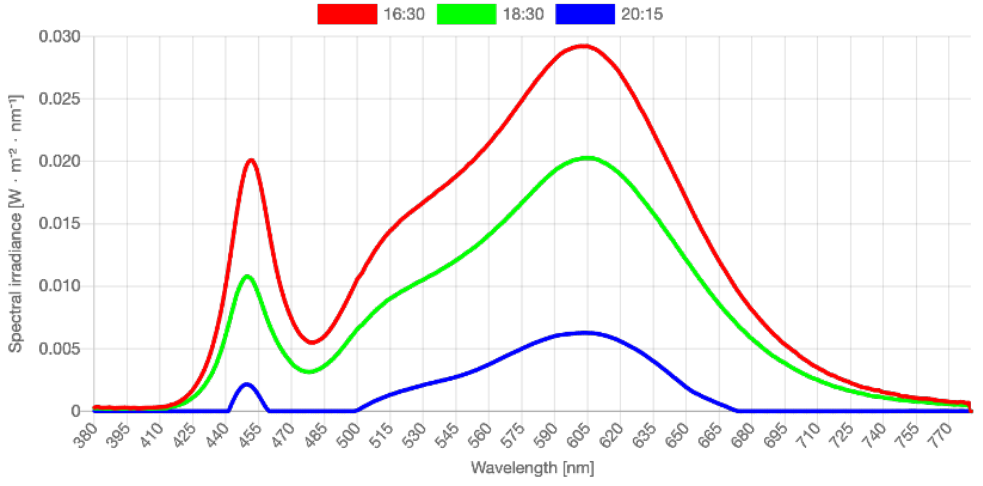

Figure 2b. Spectral distributions measured in the middle of dynamic phases as reported in Table 2: measured at 16:30 p.m., 18:30 p.m., and 20:15 p.m.

Note: Full stimulus specification tables and spectra are publicly available via the OSF [41]. Graphs and stimulus specifications were generated with the Luox platform (Spitschan, 2021), companion paper (Spitschan et al., 2021).

The LIFX-A60 LED-based light bulb was placed on a bedside table in the bedroom and offered a wake-up scenario of 30 min constant lighting in the morning. We used a light intensity of 770 lumen and a colour temperature of 7500 K.

4.2.5 Measurements

In order to obtain objective measurements of the received amount of light and colour temperature of each participant, lighting measures were collected using a spectrometer and personal light buttons.

4.2.5.1 Baseline Light Measurements of the Home Situation Using a Spectrometer

In both the control condition and the exposure condition, in every individual's home, the light intensity in lux, the colour temperature in Kelvin, and the EDI_{mel}, based on the visual colour spectrum, were measured vertically at eye level in a baseline measurement in the morning between 9:00 a.m. and 12:00 noon. The lighting measurements at home were collected with a Sekonic C-700 spectrometer. The measurements also included contributions of daylight and additional lighting routinely used in the home. Vertical measurements at eye level approach the real-life situation of light collected by the retina.

4.2.5.2 Personal Light Measurements during the Day Using a Sensor Button

To objectively measure the light received by each individual participant, a LYS button 1.0 sensor, app, and data services of LYS Technologies were used. This small device was placed as close to the participants' eyes as possible, mainly on their collar and sometimes on their glasses. The button was placed in a charger on the bedside table during the night. The button used a Bluetooth connection to connect with a smart device (Figure 3). The spectral range from the LYS RGB sensor was from 350 to 750 nm. The illuminance range of the button was 0–100,000 lx. The measurements of colour temperature were in Kelvin. Separate R, G, and B values were also recorded, but not analysed or discussed in detail, as these were used to estimate CCT. A summary table is included in the Supplemental Materials (Tables S1–S3). The device also contained a three-axis accelerometer as a proxy for activity. These data were used to indicate whether a lux value of (close to) 0 was valid, as it was unlikely that the participants moved during daytime in complete darkness. Data were sampled every 15 s.

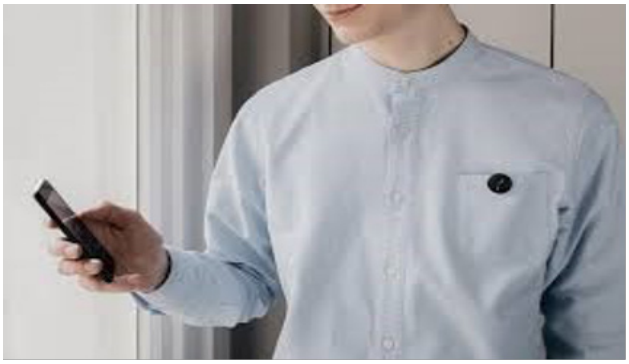

Figure 3. The LYS button sensor

4.2.6 Statistical Analyses

4.2.6.1 Preparations

In order to analyse the light data, several steps were taken. First, for illuminance, negative values and values close to 0 indicate that there is hardly any light, which is unlikely since the sensor was only worn during daytime and evening. These values were replaced for missing values as the most likely explanation is that people covered the sensor with some clothes. Therefore, we assumed these close to 0 values to be invalid. When people move, it is even less likely that they do this in complete darkness. Therefore, we used different threshold criteria for movement vs. no movement. When the participants moved, values below 10 were assumed to be invalid, but when they did not move, values below 5 were assumed to be invalid. Second, for illuminance, an upper bound value of 1000 lx was used. This was because the visual system likely saturates above this level. Third, the illuminance and RGB levels were log10 transformed in order to make the data less skewed. Finally, the data were aggregated to daypart level. That is, for each of the 7 days the sensor button was worn, there were three measurements that indicated the average light measures during the morning, afternoon, and evening.

4.2.6.2 Randomization Tests

As the number of participants was small, the distributional assumptions of a parametric analysis, such as a mixed regression, could not be warranted. We therefore used a randomization test procedure. This randomization test was used to compare the different light measures for phases A_1 and B_1, B_1 and A_2, and A_2 and B_2 at the individual and group levels.

4.2.6.2.1 Randomization Test between Participants for the Spectrometer Data

For the spectrometer, there was one observation per light condition per participant at baseline. For each room, we randomly resampled all illuminance, EDI_{mel}, and CCT values of the A and B phases for all participants to create a randomised distribution. The observed mean difference

between the two phases of A and B was compared with the randomization distribution, and the statistical significance was calculated by dividing the number of random mean differences that were equal to or larger than the observed mean difference. A type 1 error rate of 0.05 was used as the criterion to reject the null hypothesis (H0).

4.2.6.2.2 Randomization Test within Participants for the Sensor Button Data

In the randomization test, the mean difference between the observations within two phases was compared with a randomised distribution of random mean differences, which were formed by randomly resampling, without replacement, all observations within the two phases for a participant. The statistical significance could then be calculated by dividing the number of random mean differences from the randomised distribution that were equal to or larger (or smaller when the observed mean difference was negative) than the observed mean difference. Note that because the randomised distribution was not necessarily symmetric, the statistical test was one directional. In addition, H0 was not—as usual—that the mean difference between the two phases is 0, but instead that the observed mean difference does not differ from a mean difference in which the observations were randomly assigned to one of the two phases (Bouwmeester & Jongerling, 2020).

Each individual p-value shows whether a statistically significant effect was found for each individual. The power to find a significant effect for just one individual is low when the number of measurements within an individual is relatively small (i.e., <20). Therefore, we used a more lenient type 1 criterion of 0.1 to reject the null hypothesis at the individual level. By combining the results at the individual level, we evaluated the group effect for all the participants together using a replicated single-case design. The overall p-value for the replicated single-case design can be calculated by using the property of p-values that they are uniformly $[0,1]$ distributed. When the overall null hypothesis is true, the sum of the p-values is just a random draw from all possible sums of p-values.

Then, the overall p-value is the proportion of combinations of p-values that would give a sum S as small as the observed sum S_{obs}:

$$P(S \geq S_{obs}) = \sum_{k=0}^{S} (-1)^k \binom{n}{k} \frac{(S-k)^n}{n!}$$

in which k are integers starting at 0 and with the maximum closest integer being smaller than S. The use of this equation in randomization testing is explained by Onghena et al. (2005). This overall p-value from the replicated single-case design has much more power since it is based on multiple participants. Therefore, a common type 1 error rate of 0.05 was used.

We used this randomization test procedure to compare the different light measures for phases A_1 and B_1, B_1 and A_2, and A_2 and B_2.

4.2.6.3 User Experiences

As the aim of this study was to investigate whether the study protocol is suitable for field studies in the home setting, it was also important to evaluate the subjective experience of the participants in participating in such long-lasting intensive research. Immediately upon completion of the study, the participants were asked about their experiences with the study setup and the duration. In addition, 6 months after finishing the study, the participants and caregivers received an evaluation form that included questions about their experiences with the lighting system. These questions were about whether people found the light pleasant, unpleasant, or distracting; whether they felt it had affected their well-being; whether they would like to purchase the lighting system themselves; and whether they missed the lighting system after the study.

4.3 RESULTS

4.3.1 Effectiveness of the Light Intervention

4.3.1.1 Spectrometer

The spectrometer collected data in one baseline measurement to compare the intensity and CCT of the light in the three rooms of each participant's home for phases A_1 and B_1.

For each of the three rooms, a randomization test was performed to test the significance between the A (without lamp) and B phases (with lamp). The results for illuminance, CCT, and EDI_{mel} are shown in Table 3. For the kitchen, the observed mean difference in illuminance was 674 lx, $p < 0.001$ (356 lx EDI_{mel}), with higher values in phase B. For the bedroom, the observed mean difference in illuminance was 1261 lx, $p < 0.001$ (653 lx EDI_{mel}), with higher values in phase B. For the living room, the observed mean difference in illuminance was 812.7 lx, $p = 0.03$ (559 lx EDI_{mel}), with higher values again in phase B.

For the kitchen, CCT remained virtually unchanged (−28 K, $p = 0.532$). For the bedroom, CCT was 567 K higher, though this difference was not statistically significant, $p = 0.169$. The same holds for the living room, where the average CCT was lower (−431 K), though not significantly so, $p = 0.88$.

The EDI_{mel} differences were substantial. The observed mean differences in the kitchen, bedroom, and living room were 356, 653, and 559 lx, respectively, with significantly higher values in phase B.

Table 3. Results of the illuminance, CCT, and EDI_{mel} spectrometer values in phases A_1 and B_1 for the kitchen, bedroom, and living room measured vertically at eye level.

	Illuminance (in lx)						**CCT (in lxK)**						**EDI_{mel} (in lx)**					
	Kitchen		**Bedroom**		**Living Room**		**Kitchen**		**Bedroom**		**Living Room**		**Kitchen**		**Bedroom**		**Living Room**	
	A_1	**B_1**	**A_1**	**B_1**	**A_1**	**B_1**	**A_1**	**B_1**	**A_1**	**B_1**	**A_1**	**B_1**	**A_1**	**B_1**	**A_1**	**B_1**	**A_1**	**B_1**
pp1	41	777	41	194	16	540	5924	4465	4516	6704	3820	3152	40	556	32	195	27	263
pp2	195	818	24	919	3000	3550	3603	3909	4444	4456	4122	4104	121	520	19	659	2131	2496
pp3	847	724	3	2030	23	324	3149	3115	1600	6214	3507	4178	444	378	2	1829	18	192
pp4	48	1280	26	1320	50	2140	5029	4180	4057	4620	4300	4218	41	853	18	964	36	1413
pp5	48	577	2	2720	5	1300	3270	3884	1600	3424	2582	4181	28	371	0	1377	1	854
pp7	114	710	47	766	82	575	5085	4337	4782	3498	4874	4247	95	489	38	430	69	390
pp8	43	982	53	2120	110	1360	2894	4115	5368	3521	4086	4193	20	634	47	1165	72	892
pp9	37	745	15	2170	87	761	4386	4246	4814	3459	5653	4386	25	558	13	1172	81	528
pp10	11	972	20	766	95	1210	3786	4140	4690	3465	5629	4453	7	631	16	416	77	860
pp11	133	528	3	105	35	548	4388	3621	1600	3357	6018	3350	102	319	3	56	34	299
pp12	8	584	11	1000	5	140	2661	3853	2429	3417	3594	2983	54	321	1	54	20	248
MeanDif		674		1261		813		−28		567		−431		356		653		599
Sig.		<0.001		<0.001		0.03		0.532		0.169		0.88		0.002		0.004		<0.001

Spectrometer Conclusion

The results of the spectrometer data show that in the rooms in which the participants lived, the amount of light was significantly and substantially higher in the intervention condition, measured at the projected eye position of the participants. This is true for both traditional illuminance measures and melanopic EDI, which accounts for both intensity and spectrum changes with regard to melanopic activation of the photoreceptors that project to the biological clock. For all individual participants, the vertical illuminance values were higher in phase B than in phase A for all rooms with the exception of one kitchen of one participant. There were no significant differences in CCT between the two phases.

4.3.1.2 Personal Light Exposure Measured with Wearable Sensors

To test the hypothesis of whether the participants received more light in phases B_1 and B2, when the lighting system was present, compared with phases A_1 and A_2, when the lighting system was absent, individual light data from the light sensors that the participants wore were compared at the individual and group levels between phases. These data included data on light intensity and the estimated correlated color temperature (CCT).

Light Intensity (lx)

Table 4 shows the results of the randomization tests for illuminance (in lx, log10 transformed; see Supplementary Material Table S4 for the descriptives of lux values.). The table shows that in phases A_1 and B_1, for most participants, the light intervention did not result in illuminance values. Only participants 8 and 12 showed (marginally) significant effects. The sum of the individual p-values was 3.612 and hence is not significant, $p = 0.152$, indicating that no overall effect of the light intervention emerged in the replicated single-case design. The overall mean difference was 0.039, and Cohen's d was 0.14, indicating a small effect size. For the comparison of phases B_1 and A_2, we expected the illuminance values to decrease. Most participants indeed showed a decrease in mean illuminance value. The randomization tests showed that there was a significant decrease for participants 1, 2, 4, and 7. The sum of all individual p-values, 3.159, was significant, $p = 0.02$. The overall mean difference was −0.111 (log10 of illuminance), and Cohen's d was 0.355, indicating a small-to-medium effect size. The comparison of the second baseline A_2 and the reintroduction of the lamp in phase B_2 showed higher illuminance values for most of the participants, except for participants 2 and 5. The randomization tests showed that these differences were significant for participants 1, 3, 4, 6, and 10. The sum of all individual p-values, 2.046, was significant, $p < 0.001$, indicating that there was an overall effect of the lighting system intervention in the replicated single-case design model. The overall mean difference was 0.142, and Cohen's d was 0.367, indicating a small-to-medium effect size.

Table 4. Mean lx log10 values and mean differences and p-values for all phases.

	A_1	B_1	A_2	B_2	B_1–A_1		A_2–B_1		B_2–A_2	
Participant[1]	**Mean**				M_d	p [2]	M_d	p	M_d	p
pp1		1.40	1.21	1.35			−0.20	0.022*	0.14	0.031*
pp2		2.29	1.84	1.50			−0.45	0.007*	−0.34	0.989
pp3	1.78	1.63	1.70	1.87	−0.15	0.763	0.08	0.742	0.17	0.074*
pp4	1.79	1.79	1.58	1.82	0.00	0.481	−0.21	0.035*	0.24	0.041*
pp5	1.80	1.67	1.63	1.61	−0.13	0.853	−0.04	0.339	−0.02	0.551
pp7	1.96	1.92	1.65	2.07	−0.04	0.678	−0.27	0.008*	0.41	0.001*
pp8	1.54	1.83	1.72	1.84	0.29	0.003*	−0.12	0.127	0.12	0.152
pp9	1.44	1.55	1.65	1.77	0.11	0.151	0.11	0.816	0.12	0.161
pp10	1.49	1.52	1.58	1.74	0.02	0.368	0.07	0.795	0.16	0.044*
pp11	2.28	2.35			0.07	0.247				
pp12	1.68	1.85	1.77	2.20	0.17	0.068*	−0.08	0.268	0.43	0.002
Overall Effects										
Mean difference [3]					0.039		−0.111		0.142	
Cohen's d [3]					0.135		0.355		0.376	
Sum p					3.612		3.159		2.046	
Overall p					0.152		0.02		<0.001	

[1] Participants 1 and 2 had no valid observations for phase A1. Participant 6 dropped out of the study. Participant 11 had no valid observations for phases A2 and B2. [2] Individual p-values below 0.1 are marked with an asterisk. [3] Note that the overall mean difference and Cohen's d were not used in the randomization test.

Light Intensity Conclusion

The difference in the light intervention between the first control phase A_1 and the intervention phase B_1 was not significant, but the light intensity was significantly higher in phases B_1 and B_2 than in phase A_2. As full spectral data, unfortunately, could not be acquired with these wearable sensors, similar analyses could not be performed for EDI_{mel}.

Correlated Color Temperature (CCT)

The mean differences between the CCT values in phases A_1 and B_1 showed significant differences for participants 9, 11, and 12 in Table 5. The sum of all individual p-values was 4.41, which was not significant, p = 0.458. The overall mean difference was 39, and Cohen's d was 0.065, indicating a very small effect size.

For the comparison of B_1 and A_2, the randomization tests showed that there was a significant decrease for participants 1, 2, 3, 4, 5, and 7. The sum of all individual p-values was 2.68, which was significant, p = 0.005. The overall mean difference was −184 K, and Cohen's d was 0.350,

indicating a small-to-medium effect size. The comparison of phases A_2 and B_2 showed significantly higher CCT values for participants 3, 5, 7, and 9. The sum of all individual p-values was 1.19, which was significant, $p < 0.001$. The overall mean difference was 268 K, and Cohen's d was 0.469, indicating a medium effect size.

Table 5. Mean Kelvin values and mean differences and p-values for all phases.

	A_1	B_1	A_2	B_2	B_1–A_1		A_2–B_1		B_2–A_2	
Participant [1]	**Mean**				M_d	p [2]	M_d	p	M_d	p
pp1		3896	3208	3460			−687.93	0.01*	251.97	0.131
pp2		4512	4215	4300			−297.42	0.01*	85.29	0.244
pp3	3779	3687	3324	3566	−91.78	0.608	−362.91	0.03	241.96	0.059*
pp4	4137	4259	3845	4179	121.77	0.274	−413.24	0.06*	333.86	0.119
pp5	4522	4249	3814	4069	−273.02	0.899	−435.08	0.01	254.69	0.096
pp7	4325	3898	3688	3880	−426.61	0.986	−210.23	0.06*	191.60	0.061*
pp8	4010	3844	4358	4609	−165.99	0.806	514.08	0.99	250.51	0.187
pp9	3410	3847	3801	4370	437.29	0.01	−45.60	0.4	568.33	0.003
pp10	4060	3859	3918	4249	−201.08	0.759	58.74	0.59	331.45	0.111
pp11	3676	4006			330.16	0.058				
pp12	3496	4115	4149	4319	619.53	0.007*	33.55	0.53	170.52	0.179
Overall effects										
Mean difference [3]						39		−184		268
Cohen's d [3]						0.065		0.350		0.469
Sum p						4.41		2.68		1.19
Overall p						0.458		0.01*		<0.001*

[1] Participants 1 and 2 had no valid observations for phase A_1. Participant 6 dropped out of the study. Participant 11 had no valid observations for phases A_2 and B_2. [2] Individual p-values below 0.1 are marked with an asterisk. [3] Note that the mean differences and Cohen's d were not used in the randomization test.

CCT Light Conclusion

The CCT of the light was not significantly different between the first control phase and the first intervention phase B1, but CCT was significantly higher in phases B1 and B2 than in phase A2.

4.3.1.3 Randomization Test per Daypart

In order to evaluate whether the effects of the intervention were different for the three dayparts, we performed randomization tests per daypart for all the light measures. Table 6 shows the results, and Supplementary Material Table S5 displays the descriptives. For the morning measurements, no significant differences were found between the phases. Only for the CCT measures, the differences between phases A_1 and B_1 and A_2 and B_2 reached marginal significance. For the afternoon data, all light measures showed significant differences between

phases B_1 and A_2 and A_2 and B_2. For the evening data, there were significant differences for all light measures between phases A_2 and B_2. The difference between B_1 and A_2 was significant for CCT in the evening.

Table 6. Results of the randomization tests for morning, afternoon, and evening.

	Morning			Afternoon			Evening		
	M_d [1]	Sum_p	p	M_d	Sum_p	p	M_d	Sum_p	p
Illuminance									
B_1–A_1	0.04	3.664	0.170	0.04	3.838	0.225	0.03	4.068	0.312
B_1–A_2	0.11	4.532	0.307	0.20	2.952	0.012*	0.16	3.288	0.082
B_2–A_2	0.04	4.106	0.166	0.18	2.231	0.001*	0.29	0.949	<0.001*
CCT									
B_1–A_1	257.66	3.181	0.065	−75.4	5.024	0.724	−43.88	4.496	0.498
B_1–A_2	160.08	3.945	0.126	191.62	2.739	0.006*	218.61	2.661	0.016*
B_2–A_2	68.99	3.529	0.054	125.61	3.461	0.046*	708.14	0.350	<0.001*

[1] A positive difference indicates a higher mean for the first term.

Daypart Differentiation Conclusion

The randomization tests showed that the differences between the phases were most pronounced in the afternoon for all light measures. In the evening, there were significant differences between phases A_2 and B_2 for all light measures. No differences in light measures between the phases were found in the morning.

4.3.1.4 Randomization Test of Seasonal Effects

In order to test whether there were seasonal effects, we performed a separate analysis for participants who participated from September to December and for participants who participated from January to April. Table 7 (see Supplementary Material Table S6 for the descriptives) shows that there were higher illuminance levels during phase A_1 (no lighting system) than during phase B_1 in summer–fall, though this difference was not statistically significant. For the winter–spring participants, however, the light measures showed the expected statistically significant increase from A_1 to B_1, indicating a clear effect of the lighting system intervention. With regard to the difference between B_1 and A_2, we observed statistically significant decreases in both illuminance and colour temperature for the summer–fall participants. Remarkably, there were no significant differences between B_1 and A_2 for the winter–spring measures for both light parameters. Both seasons showed (marginal) significant effects for both light parameters from phase A_2 to phase B_2.

Table 7. Results of the separate randomization tests apart for fall–winter and winter–spring.

	Summer–Fall			Winter–Spring		
	M_d [1]	Sum_p	p	M_d	Sum_p	p
Illuminance						
B_1–A_1	−0.05	2.276	0.904	0.23	0.861	0.004*
B_1–A_2	0.18	1.129	0.003*	0.10	1.981	0.487
B_2–A_2	0.10	1.683	0.031*	0.18	0.398	0.001*
CCT						
B_1–A_1	−107.15	2.823	0.920	203.98	1.592	0.082
B_1–A_2	401.14	0.178	<0.001*	−122.24	2.541	0.819
B_2–A_2	226.56	0.725	<0.001*	330.20	0.433	<0.001*

[1] A positive difference indicates a higher mean for the first term.

Seasonal Effects Conclusion

The results showed clear seasonal effects for all light measures. The sunny and clear skies in September 2019 even led to higher light values in phase A_1 than in phase B_1. At the same time, the start of the spring season in March 2020 during phase A_2 probably led to no significant differences between phase B_1 in February 2020 and phase A_2. The weather statistics showed that the mean number of sun hours during phase A_2 was 8.3 h per day compared with the mean number of sun hours during phase B_1, which was 8.1 h per day (KNMI, 2021).

4.3.2 User Experiences

Immediately upon completion of the study, the participants were asked about their experiences of participation in this quite intense longitudinal study. None of the participants or their caregivers perceived the visits by the researchers as burdensome. It was sometimes considered strange to have lights left on during the day, even when they were not at home. In one participant, the lighting program was adjusted to his or her absence on several fixed days per week. Wearing the sensors was also not considered a burden by any of the participants. However, it was sometimes difficult to realise that the sensor should not be covered by clothing and should be moved to the collar of a jacket when going outside.

The participants regretted that the lights were removed for 4 weeks and indicated that they were greatly missed. The caregivers noticed that the participants liked to spend time under the lamp and seek out the light on their own. Several participants experienced problems with the connectivity of the app, which was needed to program the bed light. For all the participants, extra personal visits for technological support were necessary, as the participants and caregivers were insufficiently technically proficient to deal with these problems by telephone help desk. The problems were usually caused by bluetooth or wifi problems. Sometimes support was also needed to be able to use the app correctly. Most participants managed to

solve subsequent problems themselves, guided by a concrete user manual. In one participant, only personal visits could solve the problem.

To learn about the experiences of the participants in this study, 6 months after the end of participation, the participants and caregivers received an evaluation questionnaire. Eight participants completed and returned the evaluation. Two participants were moved to a care home, and one of these participants was incapable of answering the questions, while the other two had deceased. Figure 4 shows the responses of the eight participants and their caregivers regarding their experiences with respect to the lighting system.

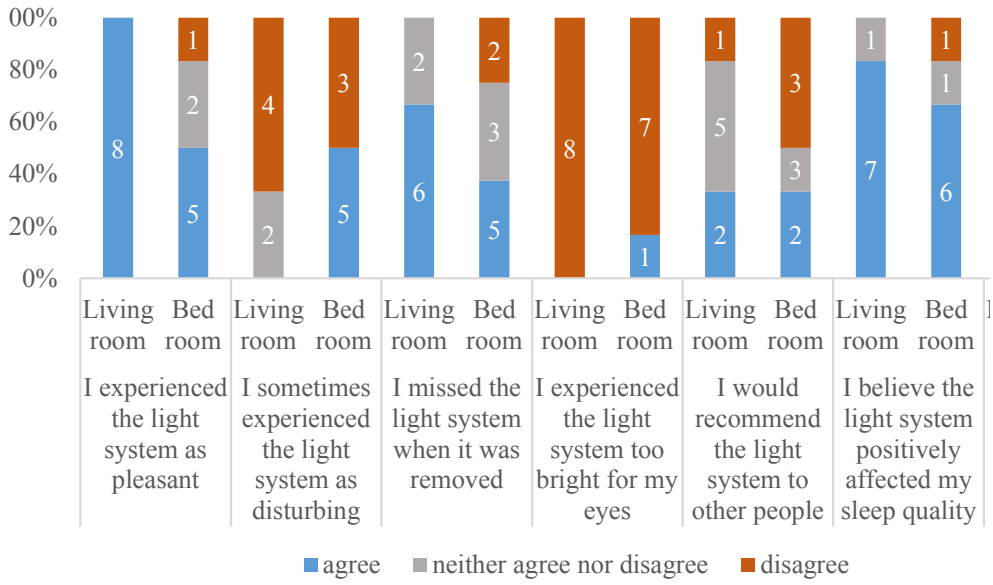

Figure 4. Responses to a short follow-up survey regarding the experiences of the participants with respect to the living room and bedroom.

As Figure 4 shows, most of the participants evaluated the lighting system as positive, and mostly not disturbing. They missed the lighting system after it had been removed. Most of the participants (or their caregivers) believed the lighting system positively affected their sleep quality and well-being. Figure 4 also shows that the participants were more positive about the lighting system in the living room than about the lighting system in the bedroom. The lighting system in the bedroom was not recommended by three of the eight participants.

4.4 DISCUSSION

The aim of this study was to investigate whether a single-case experimental design (SCED) approach, taking into account personal preferences, an uncontrolled environment, the stage of dementia, and the heterogeneity of the population, is applicable to investigate differences in light consumption for people with dementia in a real-life situation, such as a home environment. In this first attempt to do so, the lessons learned should also provide recommendations to develop a suitable light protocol to study light interventions in the homes of people with dementia.

A subsequent question was whether people with dementia living at home would be exposed to substantially brighter light and light of a higher correlated colour temperature when they used an off-the-shelf dynamic lighting system in their home compared with regular lighting. To gain more insight on its effectiveness, we also explored at what time of day the contribution of the lighting system was most pronounced (morning, afternoon, or evening) and whether the effectiveness was moderated by season. Finally, user experiences were evaluated, as their (positive) experiences ultimately determine the usefulness of the lighting solution.

It seems that the used real-life longitudinal single-case experimental design (SCED) is applicable to studying a lighting system suitable for people with dementia living at home, despite the uncontrolled environment, stage of dementia, and heterogeneity of the study population. In addition, this study approach is sufficiently sensitive for demonstrating differences in the presentation of light during the day after an exposure phase of 4 weeks in light intensity and colour.

In the following, we first discuss the results of the light intervention. After this, we reflect on the study design, including the protocol, data collection, and analyses, by discussing five reasons why the used study design is applicable and meaningful for application to this heterogeneous population. Lastly, recommendations, based on lessons learned, for future research are made.

4.4.1 Reflection on the Results

The intervention lighting that was placed in the participants' bedrooms, kitchens, and living rooms theoretically delivered up to 850 lx extra (580 lx EDI_{mel}; see Table 2, depending on the phase of the dynamic scenario) at eye level. These estimates were based on measurements in a small white room without daylight. The actual light exposure at eye level of the participants if seated correctly under the lamp, of course, depends on the exact placement of the lamp, furniture, and finishing of the room, as well as the available daylight. The measurements performed with the spectrometer in the rooms of the participants, under the lamps, indeed established an increase of 670–1250 lx (350–650 lx EDI_{mel}, depending on the room and measured in the morning, so at the peak of the scenario; see Table 3) between the

intervention and baseline conditions. However, in daily life, the actual personal light exposure largely depends on the dynamic scenario and the person's physical activity and location (e.g., spending time outdoors, opening and closing curtains, and screen usage). For instance, the added effect of the lighting system is only modest in comparison with the effect of direct exposure to daylight when people are outside. The amount of light on a sunny day is orders of magnitude higher than the amount provided by any indoor lighting system. The effectiveness of the placement of our intervention lighting furthermore depends on the time they would actually spend in the designated seating areas under the lamps. We therefore considered it important to establish the effectiveness of a light intervention in everyday situations and over a prolonged period of time.

Indeed, the personal light exposure data showed statistically significant differences between the two intervention periods and the second baseline week for most measurements. The difference in exposure in the first baseline week did not reach significance, potentially due to substantially better weather conditions in those weeks than in the remaining weeks. However, to put these findings into perspective, we should also note that the amount of extra light that was actually received according to the worn sensors was less than 20 lx (on average) during the participants' waking episodes. This is the reality of field interventions, as also observed in a recent office-based field study (Peeters et al., 2020): what you see is not necessarily what you get. On the other hand, the 20 lx may be an underestimation of the actual circadian effect, as our loggers could not collect full spectra and hence potentially did not pick up spectral shifts towards the blue spectrum specifically.

In our sample, there was actually quite some variation in the effects of the lighting system. Although most participants showed effects in a positive direction, not all individual comparisons were statistically significant, and one participant (pp3) even had lower average light exposure when the lighting system was first presented in phase B_1 and higher average light exposure when the lighting system was removed in phase A_2. A possible explanation why this individual showed this deviant pattern is that he or she was not feeling well during this period and spent a lot of time in bed, where he or she only received the 30 min of wake-up light, not the full daylight curve of the free-floor standing lights. An advantage of the SCED design is that the data can be directly linked to this participant.

An additional explanation for the differences in the results on the worn sensors compared with the results on the spectrometer is that the quality of devices to achieve an accurate quantification of light exposure can differ. Furthermore, the location where the sensors were worn can also have an impact on the results. Aarts et al. (2017) previously studied several commonly used wearable light measurement devices. They found that the quality and the outcome of these devices under different circumstances were very different, and that the

location where these devices are worn has an impact on the results. The smallest deviation, both indoor and outdoor, was found when the device was placed on the sides of the eye. In our study, one participant placed the sensor on his glasses. Other participants wore the sensor on the chest, hence less close to the eye.

The actual personal light exposure as logged by the person-worn sensors also cannot be attributed singularly to the luminaires, as they may have also varied with, for instance, changing movement patterns and weather conditions. This is why we adopted prolonged tracking within conditions and repetition within conditions. It turned out that at the group level, the introduction of the lighting system did not result in a consistent statistically significant effect across the four phases. Additional results on the subgroups showed that this absence of an effect was probably at least partially caused by the subgroup of people who started the experiment during the summer. These people even had significantly higher illuminance values during the first phase A_1 than during the introduction of the lighting system in phase B_1. The subgroup of people who started the experiment in the winter showed significantly higher levels of light when the lighting system was introduced during phase B_1. From the royal national weather station in the Netherlands (KNMI, 2021), it is known that the number of sun hours in the Netherlands at the end of the summer (September) of 2019 was much higher than in October 2019 (157.4 h vs. 99.8 h), the month in which the lighting system was introduced for the subgroup.

The limitations of the study are fairly obvious. The participants were not blind to the exposure condition, as they knew when the lighting system was present and when it was removed. They also knew when data collection took place. Hence, we cannot attribute the participants' subjective responses and experiences singularly to either the light or the mere presence and design of the luminaires. This study was conducted with a carefully selected lighting system, but other, potentially better or worse, systems could have been selected. Lighting systems could be compared by comparing one intervention with another. In addition, the target group was very heterogeneous, as often mentioned, and there were various external influences that were hopefully all considered, but it cannot be ruled out that there were also invisible confounders. People with dementia are not always able to put themselves and what is going on inside them into words. More field studies should be performed to define the best applicable study protocol for this population.

4.4.2 Reflection on the Used Design

Installing a novel lighting system in the houses of people with dementia does not guarantee that the lighting system will be used in a proper way. For example, the bedroom light worked with Wi-Fi and a Bluetooth connection, and sometimes it was accidently disconnected or

turned off by the participants. Problem solving required physically reconnecting the system, which was only possible during home visits.
The wearable sensors that objectively measured the amount of light regularly registered negative or unrealistically low values. Perhaps the sensor was partly or completely covered by clothing at such times or worn too close to the face so that there was a shadow on the sensor. Furthermore, people sometimes forgot to wear the sensor. Probably due to attentiveness of the caregivers, no sensors disappeared, were hidden, or were thrown away. Negative or unrealistically low values can be detected in data analysis, as it is highly unlikely that the participants received no light intensity and, at the same time, were registered as moving or physically active. Therefore, the study design must take into account substantial amounts of missing data by ensuring sufficient power and/or redundancy. The used SCED design with the ABAB setup seems to be appropriate to fill these gaps (Dallery, 2013; Krasny-Pacini & Evans, 2018; Smith, 2012).

Some caregivers reported that the strange new lights in the house sometimes caused some confusion among the participants and that this did not always make them sit down in their familiar places. The caregivers sometimes tried to support or encourage the participants to continue with their usual preferred daily routine. Some caregivers encountered behavioural problems or agitation at these moments. These symptoms are common in people with dementia, and their prevalence is high also among persons still living at home. For instance, in a cross-sectional study by Huang et al. (2017), 80% of the population scored positively on the behavioural and psychological symptoms of dementia (BPSD) spectrum at the onset of the disease, and even 97.5% in the moderate stage of dementia. Nevertheless, they appreciated the lighting system as indicated in the user evaluation.

Finally, our study is a field experiment in a very heterogeneous, vulnerable, and hard-to-reach population. The results of our study have high ecological validity, much more than a fully controlled experimental design, yet confounding variables may influence the results and could have made it hard to find a statistically significant effect at the group level. However, this is an inevitable property of the population and setting. The fact that an effect of the lighting system was found despite these confounding variables shows that the effect of the lighting system is rather robust and may therefore be a real benefit in practice and the real-life setting of people with dementia at home.

4.4.3 Lessons Learned

Based on this study, some lessons learned could be formulated for the implementation of the light protocol in practice. First, implementing a lighting system in the homes of people with dementia is possible and possibly useful. However, in sunny seasons, such as spring and summer, the added value of the lighting system compared with daylight is marginal. Therefore,

it might be more useful to install the lighting system in darker seasons, such as fall and winter (Nioi et al., 2017).
Besides these seasonal effects, the results also revealed differential effects for the lighting system with respect to the parts of the day. The effect of the lighting system was most pronounced in the afternoon and mostly absent in the morning. This result may be explained by the fact that the participants tended to be more active and outside in the morning, receiving more natural daylight than in the afternoon and evening, when the sun had already set by 5:00 or 6:00 p.m. in the fall and winter months. The effects were also less in the evening, but this would be in line with recommendations and the dynamic scenario as evening light is generally considered bad for sleep. This might indicate that it is useful to emphasise to users to use the lighting system in the afternoon and evening and to stimulate these users to (continue to) go outside in the morning.

The correlated colour temperature did not significantly differ for the spectrometer results in the three rooms with and without the lighting system. This was likely caused by the fact that these measurements were taken late in the morning, when the correlated colour temperature of the scenario was close to that of standard lighting. Across the day, the scenario varied between both higher and lower CCT values, so one would not necessarily expect large overall changes.

Carefully designed technological interventions can respond to unmet needs of people with dementia and family caregivers at different stages as dementia progresses (Kieboom et al., 2019). Existing products, systems, and services are often too complex to be used by people with dementia (Astell et al., 2010). Meiland et al. (2017) found that it is very important that innovations are supported by the users, are experienced as user-friendly, and are practically feasible in terms of successful implementation. Therefore, the development of assistive technology for people with dementia needs to be evaluated in a real-life context (Koskinen & Zimmerman, 2018).

Although the evaluation of the subjective experience of the lighting system by the participants is, of course, difficult because of dementia, we were still able to gather information from most of the participants (6 out of 11) based on a short questionnaire. The vulnerability became painfully obvious with the fact that two of the people had passed away and two had moved to a care home shortly after the end of the study. The participants valued and missed the lighting system, the extra light exposure in terms of intensity and color and atmosphere, when removed. Moreover, the informal caregivers were positive, and most of them even reported a positive, though still subjective, effect on the sleep, activity, and psychological well-being of their loved ones. The vulnerability of the population and still the applicability and effect of the used study design indicate that the lighting system might be useful for people with dementia in moderate and

severe stages of the disease. This seems an important finding as care innovations for home use are mostly developed and implemented by people with dementia in mild stages of the disease.

4.5 CONCLUSIONS

The results of this single-case design study are quite promising and indicate that future field studies are welcome. It is quite a challenge to perform a SCED study in such a specific and vulnerable population in a real-life setting. Nevertheless, we believe that people with dementia, particularly those still living at home, may greatly benefit from such an easy intervention as a low-cost, easy-to-implement-and-use lighting system, and this deserves to be tested in the field.

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CHAPTER 5

IMPACT OF DYNAMIC LIGHT EXPOSURE ON SLEEP-WAKE PATTERN AND BPSD IN PEOPLE WITH DEMENTIA LIVING AT HOME

E.E. VAN LIESHOUT - VAN DAL
L.J.A.E SNAPHAAN
Y.A.W.D. DE KORT
S. BOUWMEESTER
I.M.B. BONGERS

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ABSTRACT

Dementia is related to disturbances in the sleep-wake pattern, behavioural and psychological symptoms of dementia (BPSD). These phenomena are the main reason for institutionalisation. Assistive light technology is relevant to study, as mitigation of BPSD may allow for improvement of quality of life for both people with dementia and their caregivers. Studies of dynamic light exposure in home-dwelling populations are scarce. In this single-case experimental design study, we evaluated the effects of exposure to dynamic light on the sleep-wake pattern and symptoms of depression, agitation, and anxiety in 11 home-dwelling people with dementia. A four-phase light-exposure therapy oscillating between the control and intervention waves was offered. Objective and questionnaire data were analysed and discussed. The results show that the used dynamic light system did not significantly affect the sleep variables. The severity of BPSD fluctuated in the expected pattern, reducing in intensity with increased light exposure. This pattern was significant for depression and agitation. This longitudinal study included an exploration of a low-cost assistive light intervention within a hard-to-study home-dwelling dementia population. The lessons learned are discussed and recommendations are made for future studies, as this design seems suitable for studying lifestyle interventions to support home-dwelling people with dementia.

5.1 INTRODUCTION

Behavioural and psychological symptoms of dementia (BPSD) and sleep disturbances have a significant impact on the quality of life of individuals with dementia and their caregivers (Barbe et al. 2018). This population could benefit from suitable and applicable lifestyle interventions to support them. Strong hopes have been attached to assistive technology, such as dynamic light exposure. This carefully timed light exposure, varying in intensity and/or spectral power distribution over time, resulting in modified activation of the biological clock (Kompier et al. 2020) has shown promise to help regulate sleep-wake patterns and reduce BPSD, although mainly studied in institutional contexts (Lieshout-van Dal et al. 2019). Similar effects were also reported for constant, higher light levels or short-wavelength enriched lighting in this demographic (Figueiro et al. 2014; Lieverse et al. 2011). This study focuses on the potential benefit of improving the sleep pattern and reducing BPSD in people with dementia by a transportable dynamic light system.

Multiple mechanisms may explain the effect of light on sleep and BPSD. Light information is projected directly to the biological clock, located in the suprachiasmatic nuclei (SCN) of the brain (Sollars and Pickard 2015). Disruption of the biological clock contributes to a range of health problems such as sleep disturbances, mood disorders, and even neuropsychiatric disorders such as dementia (Videnovic & Zee 2015).

Light may also have direct effects on mood and mental health via other retinal projections as shown in Figure 1 (Konjarski et al. 2018). Specifically, pathways to the brain structures of the limbic system have been identified, centres that are involved in regulating emotions and behaviour, mediating the effects of light on symptoms of depression, anxiety, and agitation (Fernandez et al. 2018; Vandewalle et al. 2011).

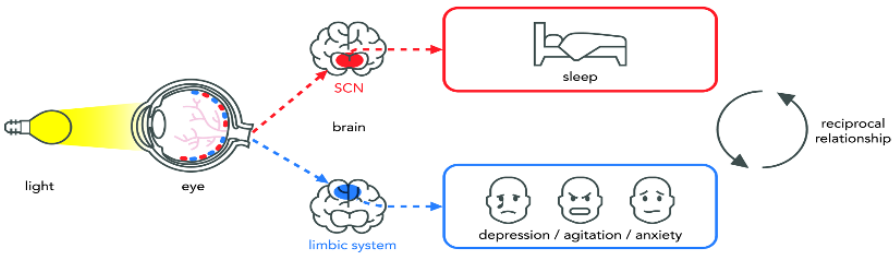

Figure 1. The influence of light on sleep, mood, and mental health via different pathways (adapted from Fernandez et al. 2018)

5.1.1 Sleep-wake Pattern and Light

Dementia can disturb the functioning of the biological clock more strongly than normal ageing can, leading to nightly wandering, daytime napping and sundowning, a phenomenon known as early-evening confusion and agitation (Hood & Amir 2017). In addition, people with dementia tend to spend less time outside. With less time spent outside, the biological clock is barely stimulated by natural daylight (Konis et al. 2018).

A promising intervention to stimulate the biological clock is light exposure with the right specifications for light level, spectrum, timing and duration. The biological clock is maximally sensitive to short (blue) wavelengths (460-480 nm) and the light level required thus depends on the exact spectrum, but is substantially higher than is commonly installed in private housing for seniors (Aarts & Westerlaken 2005). Because of the increased sensitivity of the ageing eye to discomfort glare and blinding by light, standard light therapy methods are not suitable for older adults (Konis et al. 2018). Light exposure adapted to the needs and preferences of older adults, is therefore a suitable alternative (Figueiro et al. 2015). In a recent systematic literature review, Kompier et al. (2020) concluded that only a few studies on the effects of dynamic light scenarios have been conducted.

5.1.2 BPSD and Light

BPSD is estimated to be prevalent in 90% of all patients with dementia over the course of their illness. BPSD is associated with distress among people with dementia and their caregivers, early institutionalisation, and the misuse of medication (Magierski et al. 2020).

Clinically, BPSD can be classified into five symptom domains: cognitive, motor, verbal, vegetative, and emotional (Gerlach & Kales 2020). Our study focused on the impact of dynamic light exposure on the emotional domain, specifically, symptoms of *depression*, *agitation*, and *anxiety*.

The prevalence of *depression* in people with dementia is estimated to be 30–40% (Kitching 2015). Based on a systematic review, Mitolo et al. (2018) stated that the effects of light exposure on symptoms of depression in people with dementia show a general trend toward a positive effect, even in people with dementia still living at home.

The prevalence of *agitation* ranged from 68% in home-dwelling people with dementia to 80% in people with dementia living in a nursing home. Agitation is strongly associated with lower quality of life and increased medication use (Schmüdderich et al. 2021). A study by Onega et al. (2016) showed promising results for light exposure on agitated behaviour in institutionalised people with dementia. To the best of our knowledge, no study has investigated the impact of light exposure on agitated behaviour in home-dwelling people with dementia.

The prevalence of *anxiety* varies from 8% to 81%. The large variance in these estimates may be due to the difficulty in operationalizing anxiety separately from symptoms such as depression and agitation in dementia (Kaiser et al. 2014). Kolberg et al. (2021) found in a recent randomised controlled trial (RCT) that anxiety symptoms in people with dementia in a nursing home significantly improved after light exposure.

In conclusion, assistive light technology is considered a promising intervention for affecting the sleep-wake pattern and symptoms of depression, agitation, and anxiety in people with dementia. However, there is no standard solution available, and previous studies have shown large heterogeneity (Mitolo et al. 2018). Most studies lack a complete description and motivation of the light scenario, the study design and analysis of the results (Kolberg et al. 2021; Mitolo et al. 2018). Moreover, most previous studies were conducted in nursing homes. Despite their potential efficacy, only few studies were conducted at home (Figueiro et al. 2015; Lieshout-van Dal et al. 2021).

The purpose of this study was to investigate the effects of a transportable dynamic light system, offering a scenario simulating a daylight curve adapted to the needs and preferences of older adults, on the sleep-wake pattern and BPSD in a home-dwelling population of people with dementia. Positive effects are expected to be found in the intervention phases when people are exposed to dynamic light. These effects are expected for both the sleep-wake pattern and the symptoms of depression, agitation, and anxiety.

5.2 MATERIAL AND METHODS

5.2.1 Participants

Participants were recruited using social media from September 2019 to June 2020. The inclusion criteria, assessed by a professional caregiver (i.e. geriatrist or psychiatrist), were: 1) a primary diagnosis of dementia, based on Diagnostic and Statistical Manual-V (American Psychological Association 2013) criteria; 2) home-dwelling; 3) assessed sleeping problems; 4) a score >22 on the Mini Mental State Exam (MMSE), being mentally competent to decide for themselves to participate; 5) no visual disabilities and physical independence; and 6) an actively involved informal caregiver. We excluded patients if serious eye disease was diagnosed. No restrictions were imposed on medication use. All the participants used medication at the start of the study. Medication did not change during participation.

Thirteen participants and their informal caregivers received information and were willing to participate. Both signed a written informed consent form in accordance with the Declaration of Helsinki (Seoul Revision 2008) and General Data Protection Regulation (AVG). The rationale

for including informal caregivers was to assist participants during the study in using wearables and devices. Two dyads decided to stop before data collection started because of personal circumstances. We obtained complete data for the four phases of 10 participants. One participant completed two out of the four phases and decided not to continue. Table 1 presents the participants' descriptions.

Table 1. Participant demographic variables at baseline (N=11)

		Dementia Type		Medication		Mean age (SD)	Mean MMSE-score (SD)
Male	6	Alzheimer	8	antidepressant	6	78,1	24,55
Female	5	Lewy Body	2	anxiolytics	3	(8,56)	(2,3)
		Frontotemporal	2	sedative	5		

The study protocol was approved (23 April 2015) by the institutional review board of the Mental Health Care Institute Eindhoven (GGzE) and the Medical Ethics Review Committee (MERC, METC in Dutch) of Noord-Brabant (29 August 2015 P1826), Netherlands.

5.2.2 Design and Procedure

In the current study, a single-case experimental design (SCED) was chosen in which the results were analysed by randomisation testing, aiming to combine the advantages of an RCT with those of a real-life field study. In SCEDs, a small number of patients undergo repeated measurements during the control and intervention phases (Smith 2012). Although the external validity of the SCED is low, it combines high ecological and internal validity.

A four-phase reversal control-intervention setup ($A_{1(regular\_light)}$ $B_{1\ (intervention\_light)}$ $A_{2\ (regular\_light)}$ $B_{2\ (intervention\_light)}$) was used to evaluate the effect of dynamic light exposure on sleep-wake variables and symptoms of depression, agitation, and anxiety (A_1 vs. B_1; A_2 vs. B_2), and the reversal effect of the removal of the dynamic light system (B_1 vs. $A_{2)}$.

Participants started in the control phase A_1 and received only natural daylight or light from their own light systems. Every phase had a duration of four weeks, because this time is needed to adjust the biological clock in people with dementia, although Sekiguchi et al. (2017) showed effects within two weeks. To minimise carry-over effects between phases and minimise participant burden, only the last week of each phase was used for the sleep and light data collection. Similar exposure periods and measurement protocols were successfully implemented by for instance Figueiro et al. (2014, 2019, or see Jao et al. 2022 for a review).

An off-the-shelf transportable dynamic lighting system was used. The lighting system followed a daylight curve in terms of timing, duration, level and spectrum. In our previous study, we found that this lighting system was effective in delivering significantly higher light intensities and correlated colour temperatures in both exposure phases than in the second baseline lighting phase (Lieshout-van Dal et al. 2021).

A timer switch was connected to all three light systems with a program tailored to the personal preferred day rhythm of each participant. Participants received a wearable light sensor button (LYS) that was connected to an app and placed as close to the eyes as possible, usually on the collar. The researcher installed the app on a smart device, and participants received instructions on how to use the app. During the last week of each phase (control or intervention), the participants wore the light sensor button from the moment they woke up until the moment they went to bed. During the study, a help desk was offered to resolve technical problems.

5.2.3 Testing Measures

Dynamic Light Systems for Home Use

In this study, a Waldmann visual timing light lamp (VTL-lamp) and a LIFX-A60 light bulb, shown in Figure 2, were used. The VTL-lamps were placed in the kitchen and living room near the seats where the participants spent most of the daytime. These luminaires provided both direct and indirect lighting.

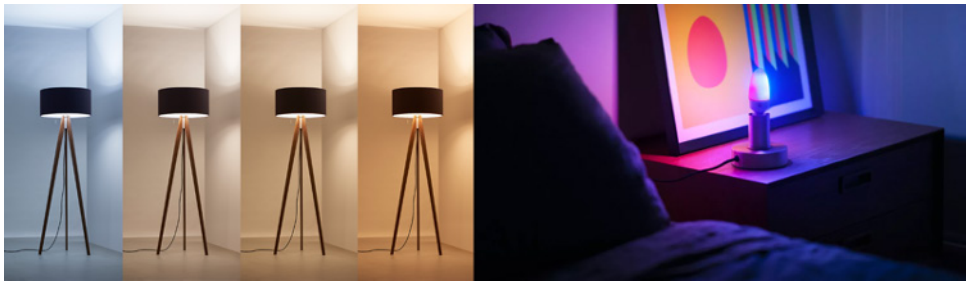

Figure 2. The used lighting system: on the left the Waldmann VTL-lamp, on the right the LIFX dynamic light bulb

The illuminance level and colour temperature of light varies dynamically throughout the day. The exact light levels on the eye depend on the exact seating position of the person, ceiling height, colouring, furniture shape, and texture, and are estimated in detail in Appendix Table A1. From 7 to 7:30 AM, the light level increased until its peak value of 2500lx. It remained until 3:30 PM, when it gradually started to decline, reaching 0lx at 9 PM. The correlated colour temperature (CCT) started high in the morning at 6000K and then gradually decreased to

normal white light (4000K) and remained there until 4 PM. In the late afternoon and early evening, it slowly lowered to a warm, yellowish light (2500K). Measurements were taken horizontally, approximately at the height of the lap of a seated individual, and vertically, approximately at the height of the eyes of a seated individual. As light may have both visual and non-visual effects on people, pathways of which both start in the eye, but are driven by different photoreceptors in the retina (Kort & Veitch 2014), we report traditional light level (lx) and CCT (the colour appearance of white LEDs). Whereas visual experiences are driven mainly by the classical cone and rod receptors, the primary drivers of so-called non-visual effects are the ipRGCs, representing a photoreceptor class that was discovered some 20 years ago only and has a different sensitivity curve than the classical receptors (Berson et al. 2002). Where full spectral data were available, we also therefore also report the melanopic equivalent daylight intensity (EDI_{mel}), as this captures the effective irradiance of the light (that is, including also the effect of the changing wavelengths in the light spectrum) for the biological clock most accurately according to the International Commission of Illumination (CIE) (CIE. 2019).

The LIFX-A60 light bulb was placed on a bedside table in the bedroom and offered a 30 min wake-up scenario of exposure to 770 lumen and 7500 K, corresponding to very cool light to boost the circadian rhythm.

Baseline light measurements

In both the control and intervention phases, in each individual's home, light level, CCT, and EDI_{mel} were measured vertically at eye level in a baseline measurement in the morning between 9 AM and 12 AM using a Sekonic C-700 spectrometer. Measurements also included the contributions of daylight and additional lighting routinely used in homes. The results are presented in Table A2 in the Appendix. In all the rooms, the amount of light was significantly higher during the intervention phase. There were no significant differences in CCT between the two phases.

Personal light measurements

The LYS button, app, and data services were used to objectively measure the light level received by each individual participant. The button, shown in Figure 3, uses a Bluetooth connection to connect to a smart device. It also contains an accelerometer as an indicator for movement. Data were sampled every 15 s.

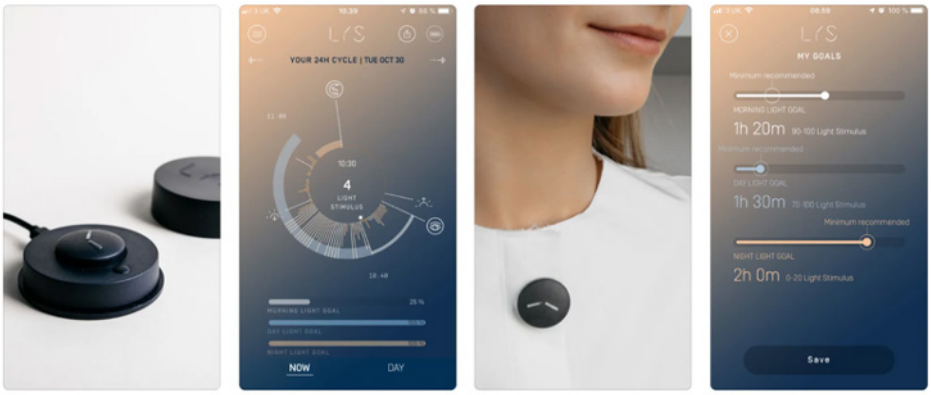

Figure 3. The LYS light sensor button

The buttons were calibrated and tested before use. Lux data were 10-log transformed to correct for skewness. We assumed illuminance values below 10, while participants were moving, to be invalid. For situations in which people were not moving, illuminance below 5 was assumed to be invalid.

Individual light data from the light buttons were compared at individual and group levels between the phases. These data include light level (lx) and estimated CCT, based on red, green, blue (RGB) data (Lieshout-van Dal., 2021, supplementary material).

Our previous study (Lieshout-van Dal., 2021) demonstrated that the participants received significantly more light in the intervention phase than in the control phase. Unfortunately, as full spectral data could not be acquired with these wearable sensors, similar analyses could not be performed for EDI_{mel}. Furthermore, participants received light with higher colour temperature values in the intervention phase than in the second control phase.

5.2.4 Outcome Measurements

Sleep-Wake Pattern

The sleep-wake pattern was measured using McRoberts MoveMonitor. The device was worn on an elastic strap on the lower back and objectively measures sleep movement, body posture, and physical activity during day and night. The move monitor has been validated (Gloeckl et al. 2015).

Data from seven consecutive days and nights during the last week of each phase were used. The primary measure was the number of minutes a participant had *night rest*. Night rest was recorded as the longest period of three hours or more, not interrupted for more than 30 min

by another activity, such as a toilet visit or awakening. This was computed as the total number of minutes lying minus the total number of minutes of movement. Because the data were skewed, we used the median in the randomisation tests. Secondary sleep measurements are transitions, times and duration out of bed, duration upright and movement.

Depression, Anxiety, and Agitation
Participants, along with professional caregivers, completed questionnaires on depression and anxiety. The informal caregivers completed a questionnaire on agitation.

- Geriatric Depression Scale (GDS-15). The GDS-15 is a short 15-item instrument specifically designed to assess depression in geriatric populations (Yesavage et al. 1982).
- Hospital Anxiety and Depression Scale, Anxiety Subscale (HADS-A). The HADS-A is a 7-item scale, frequently used for individuals with dementia (Zigmond and Snaith 1983).
- Cohen-Mansfield Agitation Inventory (CMAI). The CMAI is a 29-item scale developed to assess agitation in institutionalised older adults (Cohen-Mansfield 1989).

Sum scores on each of the three scales were employed as indicators of BPSD: $BPSD_{Depression}$, $BPSD_{Anxiety,}$ and $BPSD_{Agitation}$.

5.2.5 Statistical Analyses

As the number of participants was small, distributional assumptions of the parametric analysis were not warranted. Therefore, randomisation tests were used to compare the phases. For the primary and secondary *sleep-wake variables*, we observed seven observations within each phase. The power to find a significant effect for just one individual was low because the number of measurements within each phase was relatively small. Therefore, we used a more lenient type-1 criterion of .1 to reject the null hypothesis at the individual level. In the randomisation test, the median difference between the two phases was compared to a randomisation distribution of median differences formed by random resampling, without replacement; all measurements were observed within the two phases for one participant. The *p*-value was then calculated by dividing the number of median differences from the randomisation distribution that were equal or larger (or smaller when the observed median difference was negative) than the observed mean difference (Bouwmeester & Jongerling 2020).

Each p-value indicates whether a significant effect was found for each individual. By combining the results at the individual level, the meta-effects for all participants can be evaluated using a replicated single-case design.

For the *BPSD variables*, we used a between-subject randomisation test to test the differences between phases and tested whether the expected trend was significant. The expected pattern

showed a positive trend from phase A_1 to phase B_1, a negative trend from phase B_1 to phase A_2, and a positive trend when the light system was reintroduced in phase B_2.

For each BPSD variable, we randomly resampled all observations of all phases for all participants to create a randomisation distribution. The observed mean differences between the phases T_0 and A_1, A_1 and B_1, B_1 and A_2, and A_2 and B_2 were compared to the randomisation distribution, and the *p*-value for each comparison was calculated by dividing the number of random mean differences that were equal to or larger than the observed mean difference. A type one-error rate of .05 was used as the criterion to reject the null hypothesis.

5.3 RESULTS

5.3.1 Sleep Duration and Sleep Disturbance

Primary and secondary measures were distinguished to investigate the effect of light intervention on sleep-wake patterns. Boxplots of every sleep variable are presented in Appendix A3.

Table 2 shows the results of the randomisation test for primary sleep variable *minutes of night rest*, figure 4 shows a boxplot of the results. Although it was hypothesised that the minutes of night rest would increase during phase B_1, this effect was not observed for most participants. The overall *p*-value was not significant (Sobs = 5.37, p =.447), indicating that the *minutes of night rest* did not differ between phases A_1 and B_1. Only one participant showed a significant increase in individual analyses. The expected decrease in minutes of night rest was also not found from phases B_1 to A_2 (Sobs = 4.88, p =.450), although there were significant differences for participants 3, 4, and 12 in the expected direction. Finally, no significant increase in the *minutes of night rest* was found from phases A_2 to B_2 (Sobs = 4.86, p =.440). None of the participants showed an expected significant increase in the number of *minutes of night rest*.

Table 2. Median Minutes of Night Rest per Phase per Participant and the p-Values from the Randomization Tests

	A_1	B_1	A_2	B_2	B_1-A_1		A_2-B_1		B_2-A_2	
Participant[a]	**Median**				**Diff.**	**p**	**Diff.**	**p**	**Diff.**	**p**
pp1	267	372	393	400	105	0.180	21	0.577	7	0.459
pp2	447	475	466	488	28	0.173	-9	0.314	22	0.256
pp3	593	558	393	483	-35	0.887	-165	0.088*	90	0.200
pp4	642	625	605	619	-17	0.915	-20	0.071*	14	0.225
pp5	269	267	277	261	-2	0.517	10	0.618	-16	0.688
pp7	383	492	509	528	109	0.065*	17	0.819	19	0.278
pp8	459	147	187	100	-312	0.983	40	0.749	-87	0.898
pp9	519	505	525	480	-14	0.73	20	0.790	-45	0.861
pp10	583	598	663	604	15	0.41	65	0.799	-59	0.872
pp11	537	547			10	0.382				
pp12	387	429	368	440	42	0.128	-61	0.059*	72	0.123
Median	485	481	461	471						
S_{obs}[b]						5.37		4.88		4.86
p_{S^3Sobs}						0.447		0.450		0.440

[a] Participant 6 stopped and participant 11 had no valid observations in phases A_2 and B_2

[b] S_{obs} is the sum of all *p*-values of the participants

* p<.1

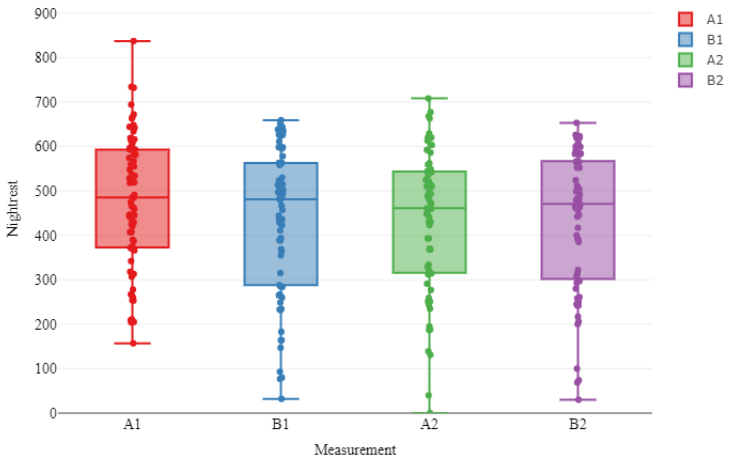

Figure 4. Boxplots of the median minutes of night rest for the four phases aggregated over participants.

None of the secondary sleep variables at the group level showed significant differences between the phases (results in Appendix A4).

5.3.2 Depression, Anxiety, and Agitation

Table 3 shows the results of the randomisation test (mean and standard deviation results in Appendix A5). The randomisation tests showed no significant differences between the phases, except for the CMAI scores between phases A_1 and B_1 (mean difference = 6.91, p =.02).

Many mean differences had the expected direction. For GDS-15, HADS-A, and CMAI, lower means were expected in B_1 and B_2 than in A_1 and A_2. These results showed a significant difference in the direction of the means of *depression* (GDS-15) and *agitation* (CMAI).

Table 3. Results of the Randomization Tests for Psychological Wellbeing Measures

	T_0-A_1		A_1-B_1		B_1-A_2		A_2-B_2		Pattern	
	Diff.	**p**	**Diff.**	**p**	**Diff.**	**p**	**Diff.**	**p**	S_{obs} [1]	p_{S^3Sobs}
GDS15	-0.64	0.360	1.27	0.235	-2.21	0.096	0.80	0.324	0.65	0.047*
HADSA	0.73	0.645	1.00	0.317	-1.35	0.256	0.00	0.505	1.08	0.208
CMAI	-1.73	0.315	6.91	0.021*	-3.53	0.155	0.60	0.432	0.61	0.038*

[1] S_{obs} is the sum of the three *p*-values for phase comparisons A_1-B_1, B_1-A_2, and A_2-B_2.

*p<.05

5.4 DISCUSSION

5.4.1 General Discussion

The purpose of this study was to investigate the effects of a transportable dynamic light system on sleep-wake patterns and BPSD in a home-dwelling population. Light studies focusing on this complex and vulnerable population are scarce or lack a complete description and analysis of the light scenario and results (Kompier et al. 2020).

In an earlier study, we demonstrated that despite the complexity of the study population and different individual circumstances, the light system was effective in delivering more light during the intervention phases. It was also demonstrated that the study design was suitable and applicable to this hard-to-study population (Lieshout-van Dal et al. 2021).

Findings on Sleep

The sleep-wake pattern did not improve in the current study. Neither the primary measure duration of night rest nor the secondary measures differed between the control and intervention phases. This was not what we expected based on the results of previous studies. However, most of these studies were performed in care facilities (Figueiro et al. 2019) and not in real-life fields. Figueiro et al. (2015) demonstrated the effects of lighting intervention in people with dementia living at home. In their field study, effects were shown on sleep and symptoms of depression. Similar to our study, seasonal effects had an impact on their results, and electric light could not compete with daylight. A possible, albeit partial, explanation could be that the participants in our study spent more time outside than inside during the first control phase. Lieshout-van Dal et al. (2021) reported that the lighting system did result in more light in the homes of the participants, as well as higher actual individual light exposures; however, the latter increased modestly and not consistently across all participants, seasons, and times of day. Although this resulted in a significant increase in light dosage, the increase may have been too modest to induce meaningful effects on the sleep-wake rhythm. This implies that it may be useful to focus on how to get more light exposure to the eyes of people with dementia. This can be done by offering more intense lighting or by encouraging participants to spend more time sitting under the light system. It could also be done by giving lifestyle advice to participants, for example leave the curtains open, take a morning walk outside, or sit by the window as much as possible.

Although we were unable to demonstrate the effects of dynamic light exposure on the sleep-wake pattern, one should also consider that there may be multiple causes for a reduced capability to achieve sufficient sleep, such as illness, life changes, environmental circumstances, and nutrition (Neikrug and Ancoli-Israel 2010). For example, in our study, one participant was sick during the intervention phase and spent considerable time in bed. Finally, it is possible that the sleep measurements in this study did not reliably reflect reality. Perhaps people slept more comfortably, but this may not be reflected by the way sleep quality was measured by the movemonitor belt. Methods to objectively measure sleep do not have the accuracy and reliability of polysomnography, used in laboratory sleep research. However, this is not a suitable measurement technique for field studies in this population.

Findings on BPSD-Symptoms

An effect on BPSD symptoms was partly demonstrated in this study. Differences between the phases did not reach significance for the separate BPSD variables, except for agitation in the first intervention phase. However, the overall pattern between phases showed changes in the expected direction in every phase for all studied BPSD symptoms. This pattern was significant for symptoms of depression and agitation. This is an important finding as depression and

agitation are known to have a severe impact on quality of life and caregiver burden (Schmüdderich et al. 2021; Barbe et al. 2018).

It may be somewhat striking that improvements in BPSD symptoms emerged without parallel improvements in sleep. However, recent findings, particularly in rodent-based research may shed light on this. For instance, LeGates and colleagues (2014) and Fernandez and colleagues (2018) have reported that light influences emotion regulation directly via pathways starting in the ipRGCs, but projecting to regions other than the internal biological clock, targeting for example the lateral habenula (LHb), a region implicated in emotion regulation. What's more, activity in the LHb was accompanied by changes in depression-like behaviours (LeGates et al. 2014), and may even be necessary for the antidepressant effects of light (Huang et al. 2019). These mechanisms have to still be confirmed in human-based research however, but may also explain the findings in the current study.

The fact that not all symptoms showed significant improvement may be because BPSD-symptoms are difficult to influence over a short period of time. The treatment of these symptoms in dementia may require a long-term multiple treatment approach, such as light therapy with longer exposure periods, for example 8 weeks (Onega et al. 2016), combined with cognitive behavioural therapy (Maanen et al. 2016).

Strengths, limitations, and directions for future research
Our study sample was heterogeneous, similar to the population of older adults with dementia, implicating inter-individual variability such as lifestyle and type of dementia. An important strength of this study was the use of the SCED and its longitudinal setup. This design was chosen because it is suitable for the population of people with dementia and its ecological validity is considered high. It controls for individual nonspecific treatment effects. Of course, not every non-specific effect can be controlled. For example, seasonality plays an important role. Despite the natural behaviour of spending time outside when the weather conditions are pleasant, and the fact that inside illuminance values do not equal the outside values, we were still able to find significant differences between the regular and intervention phases.

Several studies have demonstrated that light is a promising intervention for improving the sleep-wake pattern of older adults with dementia (Goodman et al. 2019). However, most studies were unable to demonstrate a significant positive effect of light exposure (Forbes et al. 2014; Sloane et al. 2015). These studies hypothesised that the light sources used did not have a sufficiently high light output to stimulate circadian entrainment. This suggests that people with dementia can be exposed to light systems with a greater light intensity. Alternatively, we can encourage people to spend more time using a light system. Additionally, the symptoms of dementia may have deteriorated during the study period, affecting the studied symptoms. In

addition, life events can have an impact independent of the exposure phase. This emphasises the importance of lifestyle recommendations. Recommendations as to take a daily morning walk outside, place seating furniture close to the window, eat and drink healthy, use relaxation techniques, and meet other people.

Furthermore, our study was conducted during the COVID-19 pandemic. The impact of the pandemic on the results is unclear, but negative behavioural effects were expected, as people are forced to spend more time indoors. Future studies should consider the impact of seasonality on their designs. In addition, in this study, measurements were collected during the last seven days of each phase. More measurements in each phase can lead to a more complete dataset. Certain personal circumstances may have strongly influenced the dataset.

5.4.2 Conclusions

This paper contributes to the understanding of the impact of light exposure on people with dementia. The method adopted was effective in delivering more light during the intervention phases. Depression and agitation were observed to reduce in intensity in line with increased light exposure. Furthermore, this paper contributes to the understanding of designing for health interventions in real-life situations. The design of dynamic lighting scenarios aimed at enhancing vitality requires tailoring to the individual instead of the general population to create visually comfortable environments, as effects of for instance light level on visual comfort vary widely across individuals (Kompier et al. 2021). This implies that more studies on this heterogeneous sample can result in the ability to identify inter-individual variability and the development and testing of more personalised lighting scenarios. This could be a potentially valuable direction for future studies on the effects of dynamic light exposure on other symptoms of dementia. The design used demonstrated to be suitable for this purpose and could also be suitable for future studies on the impact of lifestyle interventions in this population.

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CHAPTER 6

LIGHT TO SUPPORT PEOPLE WITH DEMENTIA

FROM RESEARCH TO HOME SETTING

E.E. VAN LIESHOUT - VAN DAL
I.M.B. BONGERS
Y.A.W.D. DE KORT
L.J.A.E SNAPHAAN

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6.1 INTRODUCTION

Sleep and mental health problems are common in people with dementia and increase the risk of transition to a care setting. Scientific research in semi-controlled conditions shows that light therapy has positive effects on sleep and mental health problems in people with dementia. In-context field studies are complicated, however necessary to enable successful implementation in the home setting. This chapter describes how to conduct an in-context field study in dementia care and provides suggestions for dealing with limitations.

Dementia is a profound disease with a huge impact on the patient, their environment and society. Most persons with dementia prefer to live independently for as long as possible and the government also favours so-called ageing-in-place over institutionalisation. However, the progressive course of the disease is often accompanied by sleep problems and reduced psychological well-being, which weighs down heavily on informal carers. This burden is often an important reason why transition to a care setting is inevitable (Hjetland et al., 2020). Dementia intensifies the ageing process of the brain and the eye. Furthermore, people with dementia tend to spend less time outdoors. As a result, they do not receive enough light exposure to entrain their biological clock properly. Via this internal clock, light with the right characteristics can have a positive effect on the sleep pattern and psychological well-being. However, the standard light therapy method, a daylight lamp or light box, is not suitable for people with dementia. The ageing eye is sensitive to glare from intense and direct light exposure. In addition, it is often difficult for people with dementia to sit still in front of a lamp for a long period of time (Goudriaan et al., 2021). Light therapy interventions for people with dementia should therefore not only be effective, but also suit the users' personal preferences and circumstances. In conclusion, for the successful implementation of these kinds of innovations, scientific research in a home setting with the specific user group, such as people with dementia, is essential. It forms a crucial link between science and practice and generates results that may tangibly and substantially improve people's lives.

6.2 RESEARCH INSTRUMENTS IN THE HOME SETTING

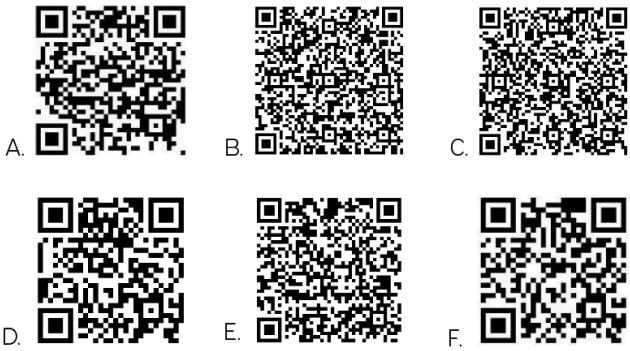
Several existing light systems designed to promote health and wellbeing are not suitable for home use, for example due to high costs and complex installation. We studied how present off-the-shelf lighting solutions for home use can support people with dementia. First, a study was performed in an inpatient ward of a psychiatric hospital, in which the participants' living conditions and daily routines were quite similar (van Lieshout et al., 2019a; van Lieshout et al., 2019b). Positive effects of the light system – improvement of sleep patterns; more rest at night, reduction of daytime napping (van Lieshout et al., 2019a) and reduced mental health problems – were demonstrated (van Lieshout et al., 2019b). However, at the same time, we encountered several issues concerning the practical execution of the study. We incorporated

the insights we gained from this study into the design of our second study, taking place in the home situation. In both studies, participants were followed for 16 weeks. Figure 1 illustrates an overview of the research instruments we employed in both studies.

Research instruments		
Clinical setting		
		
A	C	E
Home setting		
		
B	D	F

Figure 1. An overview of the research instruments in both studies. See QR-codes for more information.

Used wearables



The wearable light sensors used in the clinical study were easily lost or came undone due to their weight and means of attachment. Sensors were often forgotten or ended up in the washing machine. Sensors were sometimes taken apart or thrown away because participants mistook them for insects. To prevent this, they were decorated as personal-style brooches (Figure 2). Unfortunately, this did not help much. Moreover, the devices operated on solar cells. Due to the low light levels in the ward, they often failed to recharge during the day. Therefore, these sensors are less suitable for indoor studies. A different personal light sensor was used for the home study: a small light sensor that could be attached firmly and charged easily, and was linked to an app. This type of light sensor was not lost, forgotten or mistaken for anything else. The fact that the app made datafiles directly accessible to the researcher was very helpful in analysing the data. It was sometimes difficult for participants to connect the light sensor with the app, as they were unfamiliar and inexperienced with technology. This often resulted in the accidental disabling of Bluetooth, upon which data synchronisation failed. A helpdesk that was able to make home visits proved necessary.

The bed sensor used in the study in the clinical ward recorded data via an external cloud that appeared vulnerable to practical problems. When changing the bedding, health care professionals frequently forgot to put the plug back in. The plug was also easily pulled out by participants. Even duct tape did not prevent this. The sensor mattress was also considered to be less suitable for the home setting as many participants sleep with a bed partner. Therefore, in the home setting, we deployed a personal exercise metre, worn with an elastic strap around the waist of the person with dementia. Wearing the exercise metre was not always pleasant, due to itching or discomfort when sleeping and during toilet visits. The manufacturer is currently working on a solution by developing an adhesive motion sensor.

The questionnaires, which had to be scored every three weeks by the healthcare professional, increased the workload for staff in the clinic and made proper execution of the study challenging. In the home setting, the questionnaires were sometimes confrontational for the informal carer or the person with dementia, e.g., when asked to indicate whether life was no longer worth living because of the dementia. In response, informal carers were given the opportunity to complete the questionnaires in a separate room. Evaluation questionnaires were completed several months after finishing the study. The light system was positively appreciated by participants and informal carers. Some even purchased it themselves after the study.

Figure 2. light sensor decorated as a brooch

6.3 RESEARCH PROTOCOLS IN THE HOME SETTING

Research in the home setting in this vulnerable group of participants is valuable but rarely conducted because it can be burdensome. Despite the perceived complications and burden on the participants, they committed to the research for a long period of time, which is special and unique partly because of the unpredictable progression of the dementia process and the already high burden of care informal carers are facing. The relationship between the researcher and participants was valuable and seemed necessary for both parties during the study process. A cup of coffee and a chat, an informal phone call or card in between formal visits, provided rapport, commitment and more insight into the situation, which was important for interpreting the data. The mutually established relationship probably also contributed to the successful completion of the study. Approachability of the researcher and an easily accessible helpdesk serviced by the researcher, with possibility of home visits in case of questions or problems with the technology proved indispensable. In the evaluation, participants also indicated that their intrinsic motivation for participation in the study could be attributed to

their sense of contributing to research into a non-medicinal, supportive intervention, of feeling meaningful and useful, or to their conviction that the intervention would help.

6.4 IMPLICATIONS

The research process provided valuable insights on how commercially available, off-the-shelf light systems can be supportive for stronger sleep patterns and better psychological well-being of people with dementia, especially in certain seasons and for people who only rarely go outside (van Lieshout et al., 2019a; van Lieshout et al., 2019b; van Lieshout et al., 2021).

Both experts, researchers and care professionals, need to look beyond their own field of expertise and share each other's knowledge and experiences to advance the support for people with dementia through technology. We summarised concrete, practical recommendations for researchers and healthcare professionals based on our study results (in table 1 below).

Table 1. Recommendations for Researchers and Healthcare Professionals from Lessons Learned

Practical recommendations for researchers	Recommendations for healthcare professionals
· Choose a study design you can personalise. Maintain own habits and rhythms as much as possible · Provide wearables that are easy to use · Schedule contact moments when it suits participants · Slow down, repeat and keep calm when getting results · Take sufficient (informal) time · Acknowledge feelings of inexperience and uncertainty when using technology · Provide visual instructions for use and an accessible helpdesk · Provide sufficient spare equipment · Use of technology can sometimes be stopped for a while · Facilitate continued use of technology after the study	· Consider light therapy in people with dementia as an intervention · Choose light therapy suitable for the older eye and in dementia · Plan > 30 minutes a day of being outside in the daily rhythm, preferably in the morning · Spend sufficient time under the light system in autumn and winter · Leave curtains and net curtains open and create window seats · Encourage people to sit facing the open window · Recognise the importance of participating in research even for people with dementia themselves · Supervise and support participants during all phases of research · Assist in the personalisation and implementation of research · Facilitate the use of technology

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CHAPTER 7

GENERAL DISCUSSION

7.1 INTRODUCTION

Dementia is a severe progressive neurocognitive disorder and presents physical, psychological, social and economic challenges, not only for people living with dementia, but also for their caregivers, the healthcare system and society at large. More than 55 million people in the world live with dementia and nearly 10 million new cases are added every year (WHO, 2021). There is currently no treatment available for dementia. Due to the social and economic impact of dementia, governmental policies are focused on having people with dementia living at home as long as possible by creating a dementia-inclusive society. Living at home as long as possible is also wished by patients and caregivers. Therefore, it is a shared goal to offer appropriate support and care, and improve the quality of life of people with dementia and their caregivers at home (Sury et al., 2013; Harrison et al., 2019). This goal implies the need to study the effectiveness of supportive technological innovations in the homes of people with dementia.

Dementia is often associated with sleep disturbances and behavioural and psychological symptoms of dementia (BPSD), subsequently negatively influencing the quality of life of patients and their caregivers, and increasing the risk of transition from a home setting to a care setting. Light therapy is a promising technological innovation that has shown the potential to support people with dementia and improve their sleep pattern and BPSD, however, it has mostly been studied in clinical settings. Therefore, this thesis investigates how people with dementia still living at home could be supported by a bright light system. This thesis aimed to fill this knowledge gap and focused on the main question:

Is a transportable dynamic light system, suitable for home use, able to demonstrate a positive effect on the sleep pattern and BPSD of people with dementia in a clinical and home setting?

We addressed this main aim through five sub questions related to the use of transportable dynamic light systems to support people with dementia. The first research question addressed whether it is possible to expose people with dementia to significantly more light in a clinical setting using a transportable dynamic light system. The second research question was whether this transportable dynamic light system would have a positive effect on the sleep pattern and BPSD of people with dementia in this clinical setting. The third research question focused on how the insights obtained in a semi-controlled clinical setting would inform the design of a study suitable and applicable to investigate dynamic light therapy in the complex heterogeneous population of people with dementia living at home. The fourth research question was whether it is possible to expose people with dementia living at home to significantly more light by a transportable dynamic light system. The fifth and final research question addressed whether the light offered by this transportable dynamic light system can have a positive effect on the sleep pattern and BPSD of people with dementia living at home.

7.2 MAIN FINDINGS

In the section below an overview will be given of the main findings from this thesis on light exposure, sleep patterns and BPSD.

7.2.1 Light exposure

The first study (Chapter 2) demonstrated that there was a significant increase in light exposure in the intervention condition compared to the control condition in people with dementia in the clinical setting. Subsequently, this finding was confirmed in the home setting (Chapter 5) showing a significant increase in exposure to light in people with dementia, both in terms of increased photopic illuminance and in terms of melanopic equivalent daylight illuminance in the intervention condition compared to the control condition. It was established that the lighting system led to more light in the homes of the participants, as well as to higher actual individual light exposures. In conclusion, our findings suggest that a transportable dynamic light system can increase exposure to light in clinical settings as well as in the homes of people with dementia.

7.2.2 Sleep patterns

In the clinical setting, the first study (Chapter 2) showed that exposure to dynamic light had significant effects on various sleep pattern variables, namely frequency of nocturnal wandering, frequency of daytime napping, and number of times out of bed at night (which all reduced significantly), and nocturnal sleep duration (which increased significantly), confirming the overall positive effect of dynamic light on the sleep patterns of people with dementia in a clinical setting. In the home setting, slight improvements in sleep patterns were also observed in the intervention conditions, however these positive trends did not reach significance (Chapter 5).

7.2.3 Behavioural and psychological symptoms of dementia

In the clinical setting, the first study (Chapter 3) showed a decreased severity of neuropsychiatric symptoms in participants after exposure to dynamic light, although only disinhibited behaviour decreased in a statistically significant manner. The findings of this study demonstrate that a transportable dynamic light system has the potential to mitigate neuropsychiatric symptoms in people with dementia. However, this potential should be considered with caution as this result was modest and not confirmed in the home setting. In the home setting (Chapter 5), no significant effects could be demonstrated of the dynamic light system on symptoms of depression, anxiety, or agitation in direct comparisons between phases. However, the overall trend from the beginning to the end of the experiment did show significant beneficial effects on agitation and depression.

7.3 DISCUSSION

Studying technological innovations in people with dementia in a home setting is relevant and valuable but carries several challenges. Dynamic light exposure is mainly studied in clinical settings and not in home situations (Lieverse et al. 2011; Figueiro et al. 2015; 2019; 2020). Most light systems used in studies conducted in nursing homes are not suitable for, or transportable to, studies in home settings due to transportation or installation difficulties (Riemersma-van der Lek, 2008). Besides, standard light therapy methods are not appropriate, as they are not adapted to the needs and preferences of older adults (Konis et al. 2018). A final challenge is the complexity to conduct studies in a home setting because of the heterogeneity of the population. This heterogeneity makes it difficult to conduct a randomised controlled trial (RCT) – whereby large numbers of participants are assigned to control and intervention groups for comparison purposes. A suitable study design needs to consider that living circumstances, daily routines, the type of dementia, time since diagnosis and other personal characteristics differ per participant. Using personal wearables and sensors offers an opportunity to perform measurements that describe variables per person as accurately as possible.

7.3.1. Clinical vs home setting

Several differences between the findings of the conducted studies need to be considered first: the study in the clinical setting (Chapters 2 and 3) included a sample of participants that were quite homogeneous concerning their living circumstances and daily rhythm. Most clinical trials aim to achieve a homogenous sample because it is easy to implement and evaluate an intervention (Martínez-Mesa et al., 2016). In the home setting (Chapter 5), all participants followed their own daily schedules, making it difficult to categorise them into homogeneous strata. Furthermore, the ward used in the clinical setting was very dark during the day in the baseline condition, creating a massive difference between intervention and control conditions as well as indoor and outdoor conditions. The light intensity differences between intervention and control conditions, and indoor and outdoor environments in home settings were much smaller than in the clinical setting. Furthermore, participants in the clinical setting spent less time outside than participants in the home setting. This implies that some participants in home settings already had significant exposure to natural daylight in their everyday living conditions. These differences in lighting conditions between clinical and home settings might explain the differences in results, especially for sleep patterns.

7.3.2 Light exposure

The lighting system led to more light exposure in the homes of the participants, as well as to higher actual individual light exposures. These findings are consistent with several studies conducted by Figueiro et al. (2014; 2015; 2019) who found that a dynamic light system could be used to increase daytime light exposure in people with dementia in both clinical and home settings. The personal light meters that we used to assess light exposure showed a much more

modest estimate of light exposure than the handheld measurements. We see two potential explanations for this. The first is that the lamps were placed near the participants' favourite seats in their homes, but the distance to the eyes was not strictly prescribed and people simply do not sit all day in the same position as where the handheld measurements were taken. Because people have free mobility in their home or in the institution, light exposure will never be exactly what you measure incidentally with handheld meters or what you aim for when setting the guidelines. This has also been demonstrated in other contexts (Peeters et al., 2020). The second aspect is that the measurements with the personal light sensors may also have been biased due to limitations of the lux meter - this was shown by calibration measurements of the personal light sensors after the study. So, we did establish that participants were exposed to more light in the intervention condition through both the handheld measurements and the personal measurements. However, the estimate of the increase in personal exposure was only modest, perhaps partly rightfully because of participants' spatial movement away from the lamps, but to some extent perhaps also unjustly due to measurement error. Our findings additionally demonstrate that it is essential that personal light exposure should be properly measured with reliable and accurate loggers. In future studies, we should aim to measure not only the received personal light intensity, but the complete light spectrum as the biological effectiveness of light depends heavily on the light spectrum. In addition, the actual contribution of a lighting intervention depends on the characteristics of the selected installation, as well as the lighting conditions in the initial phase, i.e., the baseline setting, which may vary from participant to participant. Moreover, in Chapter 5 we discussed that in addition to the reliability and accuracy of wearables and sensors, their user-friendliness and attractiveness are also essential for the successful conduct of a study. It is important to consider which sensor is most suitable and applicable, and to properly instruct and guide its use by participants in order to collect valid data.

Furthermore, the use of two different transportable dynamic light systems may also (partly) explain the differences in light measurements between the clinical and home setting. The light system used in the clinical setting was able to produce higher light intensity levels than the light system used at home. Another explanation is that the distance between the light system and the participants eyes and/or the viewing direction can significantly influence the amount of light received in home settings. A limitation of our study is that these variables were not controlled for in the home setting, which might have resulted in variance. Also, the handheld measurements used in the clinical study did not control for the previously mentioned distance and mobility variability. Another limitation of our study is that seasonal and daily weather influences were not accounted for. Participants, especially in the home setting, were likely to spend more time outdoors on sunny days than on rainy days. Other explanations for the found differences in light measurements could be found in living circumstances, life events, illness, disease progression as the study period was long, COVID-19 restrictions, and less difference in

light exposure between the exposure condition compared to the regular condition in private homes than in the clinical setting. This implies that participants in the home setting received relatively less extra exposure to light than participants in the clinical setting. On the other hand, the fact that all of these events occurred and that these differences existed ultimately contributes to the ecological validity of our outcomes for a home setting and hence underline the importance of this type of study.

7.3.3 Sleep patterns and BPSD

In the clinical setting the positive effect of dynamic light on the sleep pattern of people with dementia was confirmed. These findings are consistent with Baandrup and Jennum (2021), who found that a dynamic light system in a nursing home improved sleep patterns in older people with dementia. A systematic review of 14 studies investigating the effects of dynamic light in various populations also showed a good consistency between studies in improving sleep patterns, likely due to increased light exposure in indoor environments during the day (Kompier et al., 2020). In the home setting improvements were observed on the sleep pattern, however not significant. These findings are not consistent with Figueiro et al. (2015) and Shishegar et al. (2021), who both found that a dynamic lighting system in a home setting significantly increased sleep duration in the intervention condition compared to the control condition The differences in light exposure in the clinical setting compared to the home setting might explain not reaching significance on the sleep pattern in the home setting. The dynamic light system may achieve effectiveness on the sleep pattern of people with dementia at home, if homes with dark interiors (e.g., few windows) and participants who hardly ever go outside are included. Moreover, the added value of the light system seems most prominent in darker seasons, such as fall and winter, and in the afternoon and evening. This finding is consistent with the findings of Nioi et al. (2017) who found particularly low levels of light exposure in people with dementia in winter compared to summer. The difference in received light exposure might also explain the results on BPSD showing effects in the expected direction but non-significantly in the home context, except when tested on the overall level. These findings are consistent with those of Figueiro et al. (2015), who found that a dynamic light system significantly reduced depressive symptoms in older people with dementia living at home. In addition, several studies performed in clinical settings (Figueiro et al., 2014; Hjetland et al., 2020; Goudriaan et al., 2021; Jao et al., 2022; Wahnschaffe et al., 2017) also found that a dynamic light system reduced symptoms of depression and agitation in older people with dementia. Considering that the dynamic lighting system at home did nonetheless show an overall trend in reduction of agitation and depression in older people with dementia, the intervention may still be considered valuable. However, more research is needed in home settings. For example, an extended light exposure period seems necessary as BSPD might not diminish or improve significantly within a few weeks. It is a notable finding that these improvements occurred without a parallel improvement being demonstrated in sleep patterns. This suggests that light may have positive effects through

multiple pathways. Light has an impact via the internal biological clock, as an indirect pathway. However, light could possibly also have positive effects on BPSD via other, indirect or direct, pathways circumventing the clock, as suggested by LeGates et al. (2014) and Fernandez et al. (2018). It is, therefore, promising that we may see positive effects of increased light exposure even in the absence of sleep disturbances. A limitation of our study is that we included a small sample. However, we were able to follow participants for a long period of time, which is exceptional given the progressive nature of dementia. Future research in this population including larger samples might confirm these potential promising findings.

7.3.4 Suitability and applicability of the study design

The main purpose of the home study in Chapter 4 was to assess if a real-life SCED study design can help evaluate the effectiveness of a transportable dynamic light system in a complex and heterogeneous sample of people with dementia living at home. It was observed that the used SCED study design was applicable and suitable to conduct a study of light intervention in the homes of older people with dementia. This design was suitable because the various participants acted as their own controls, making it possible to conduct a valid experiment in a heterogenous target group (Krasny-Pacini & Evans, 2018). This is also stressed by Kazdin (2019) who found a within-subject design to have better generality than a between-groups design and even stated that single case designs could play an important role by improving individual care and therapeutic change, apart from their strength as a research tool. Although the external validity of the SCED is low, it combines high ecological and internal validity as it is able to control for individual non-specific treatment effects and is therefore suitable for this study purpose (Smith, 2012).

7.4 IMPLICATIONS FOR RESEARCHERS AND HEALTHCARE PROFESSIONALS

Involving people with dementia

The diversity in the population of people with dementia with regard to several aspects, like living circumstances, personality, disease type and stage, poses serious challenges for researchers. It is of great significance to gain insight in the variety of needs, wishes and abilities of people with dementia. Involving people with dementia in the development, testing and implementation of supportive technology does not only provide these insights for researchers, but may also yield an enhanced sense of control in participants (Hanson et al., 2007) and can ultimately lead to a more empathic understanding of people with dementia (Lindsay et al., 2012). In an extensive literature review, Suijkerbuijk et al. (2019) studied current practices for the active involvement of people with dementia in the development of supportive technology and how this was experienced by participants themselves. They concluded that this remains a challenge to

date and that there is still a lack of specific knowledge on appropriate methods and materials for active involvement of people with dementia in supportive technology development. Observations and reflections that were made during our study project echoed those in this review article. An observation made was that the valuable relationship that developed between researchers and participants seems empowering and was appreciated by participants. A cup of coffee and a chat, an informal phone call or card in between scheduled meetings stimulated connection and more insight into the participants' individual situations, which is important for interpreting the data and probably contributed to the accomplishment of the study. An easily accessible help desk provided by the researcher, with the possibility of home visits in case of questions or problems with the technology, proved essential (Lindsay et al., 2012; Van Rijn et al., 2010). Participants' reasons to participate were 1) being useful by contributing to and being involved in research activities, 2) to contribute to a better quality of life for future dementia patients, and 3) to be able to give one's opinion and share experiences. Furthermore, participants also reported about the preferred characteristics of the supportive technology. In earlier studies that involved people with dementia, participants pointed out that 1) it should be possible to adjust features of the intervention to each individual's needs and wishes (Wang et al., 2017), 2) it is important that the product is appealing and attractive to use (Suijkerbuijk et al., 2015), 3) technical problems and installation errors need to be resolved (Kerkhof et al., 2015; Hattink et al., 2016), and 4) instructions need to be short, step-by-step with pictorial support, and personal assistance available when necessary (Jacova, 2015). It is important for future researchers to take these learned lessons into account when investigating supportive technology. Furthermore, it may be essential to involve people with dementia as co-designers throughout the innovation process, to ensure that innovations better address specific needs of people living with dementia (Snaphaan et al., 2022).

The increasing number of people with dementia worldwide creates a need for meaningful support in independent living and overall well-being in daily life. Besides, the possibilities of supportive technology increase with the continuous worldwide development of digitalization. Several studies emphasise the importance of involving people with dementia in the use and development of supportive technologies (Holthe et al., 2018; Meiland et al., 2017; Span et al., 2013; Topo, 2009). However, people with dementia are mostly only involved in the evaluative phase, making their role limited to being an informant (Suijkerbuijk et al., 2019). It seems complicated to allow people in the more advanced stages of dementia an active role in the process of a project that might easily take several years. However, people with dementia cannot be treated as a homogeneous group, due to the course of the disease. Therefore, it might be sensible to conduct projects that do not cover a period of several years but cover a shorter study period.

Insights

This research project provided valuable insights into how a transportable dynamic light system can be supportive for the sleep patterns and psychological well-being of people with dementia, especially in certain seasons and for people who do not spend much time outside in natural daylight. Besides, the project highlights the added value of collaboration between researchers and healthcare professionals to cope with the associated challenges in studying and supporting this population. Both experts need to look outside their own field of expertise and share each other's knowledge and experience to take the field of support for people with dementia with technology one step further.

Despite their promising benefits, the use of supportive technology by people with dementia, especially people still living at home, is limited. There is a lack of specific knowledge about appropriate and suitable methods and materials to actively involve the participants. It is crucial to involve participants in research and to support meaningful technological developments with their personal evaluations and insights. Moreover, it is important that people with dementia are supported in the use of technology, both through practical help and user-friendliness. Besides, it is also valuable that people with dementia participate in the design and use of technology. In this regard, some valuable observations were made in this project concerning the use of technology in studying this population. First, some participants expressed displeasure about wearing the light sensor and exercise meter. Second, most participants experienced difficulties using mobile devices and connecting the light sensor to the app. Third, some participants or caregivers were reluctant to complete all the questionnaires at once, as they reported that some questions were confrontational. The researchers tried to solve these issues and promote positive experiences in participants with the use of technology as much as possible. Technological interventions that are supported by the users, are experienced as user-friendly, and are practically feasible have a greater chance of successful practical implementation (Meiland et al., 2017). In our study, all participants reported to appreciate and enjoy the dynamic light system in their homes and indicated that they experienced the dynamic light system to improve their sleep and psychological well-being. Several participants purchased the light system themselves after removal. Our reflection on the importance of involving participants in the evaluation of interventions is confirmed by Koskinen and Zimmerman (2018) who stated that the development of assistive technology for people with dementia needs to be evaluated in a real-life context. Table 1 (chapter 6) summarises practical recommendations for researchers and healthcare professionals.

7.4 CONCLUSION

The use of dynamic light therapy in people with dementia is beneficial as it provides a non-pharmacological intervention. The use of medication to treat sleep disturbances or BPSD can result in undesirable side effects (Riemersma et al., 2008). Earlier studies in this domain have often used bright light therapy as an intervention to treat sleep problems and BPSD (Hjetland et al., 2020; Jao et al., 2022). However, there are several reasons to consider other bright light intervention methods in people with dementia: The ageing eye poorly tolerates direct bright light (Grossniklaus et al., 2013) and people with dementia usually cannot sit in a fixed place for a long period of time. It is essential that light interventions, used to support people with dementia, take into account their preferences, personal and living circumstances. Dynamic ambient bright light may suit people with dementia better, because it is offered throughout the day instead of on a fixed moment in time, and because it does not induce glare or light scattering in the eye.

The findings of this project demonstrated that a transportable dynamic light system could help to expose people with dementia in clinical and home settings to more light, and that subsequently this could support their sleep patterns and BPSD, especially lower levels of agitation and depression. However, the value of dynamic light systems in home settings seems higher in dark seasons when photoperiods are short, like autumn and winter, in homes with a dark interior, and in people that tend to spend hardly any time outside.

Despite the perceived complications and burden on the participants when participating in the study, they still committed to the study for a long period of time, which is special and unique, partly because no one knows how the dementia process progresses and informal carers are often already overburdened. The intention of the study and the valuable relationship the researcher developed with the participants seems necessary to complete the project for both parties. The fact of contributing to research into a non-medicated, supportive intervention, the feeling of being meaningful and useful, or the conviction that the intervention helps, gave participants intrinsic motivation for continuous participation.

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APPENDIX A

Table S1. Mean Red Light log10 Values and Mean Differences and *p*-Values for All Phases.

	A_1	B_1	A_2	B_2	B_1-A_1		A_2-B_1		B_2-A_2	
Participant[1]		***Mean***			M_d	*p*	M_d	*p*	M_d	*p*
pp1		1.29	1.25	1.35			-0.03	0.32	0.1	0.054
pp2		2.32	1.75	1.40			-0.56	0	-0.35	0.993
pp3	1.84	1.64	1.74	1.86	-0.20	0.821	0.11	0.81	0.12	0.157
pp4	1.68	1.63	1.50	1.67	-0.05	0.698	-0.13	0.1	0.18	0.094
pp5	1.67	1.60	1.61	1.55	-0.06	0.702	0.00	0.5	-0.06	0.664
pp7	2.00	1.87	1.63	2.02	-0.13	0.856	-0.25	0.01	0.39	0.001
pp8	1.40	1.70	1.56	1.78	0.30	0.001	-0.13	0.12	0.21	0.104
pp9	1.45	1.50	1.62	1.66	0.05	0.26	0.12	0.87	0.04	0.343
pp10	1.38	1.38	1.49	1.65	0.01	0.483	0.11	0.93	0.15	0.058
pp11	2.27	2.35			0.09	0.193				
pp12	1.70	1.79	1.71	2.18	0.09	0.183	-0.08	0.23	0.47	0.002
Overall Effects										
				Mean difference[3]		.001		-.084		.124
				Cohen's d[3]		.064		.263		.321
				Sum *p*		4.197		3.9		2.47
				Overall *p*		0.365		0.12		0.002

[1] Participants 1 and 2 had no valid observations for phase A_1. Participant 6 dropped out of the study. Participant 11 had no valid observations for phase A_2 and B_2.

[2] Individual p-values below .1 were shaded grey.

[3] Note that the Mean differences and Cohen's d were not used in the randomization test.

Table S2. Mean Green Light log10 Values and Mean Differences and p-Values for All Phases.

	A_1	B_1	A_2	B_2	B_1-A_1		A_2-B_1		B_2-A_2	
Participant[1]		***Mean***			M_d	*p*	M_d	*p*	M_d	*p*
pp1		1.17	1.03	1.20			-0.15	0.08	0.17	0.019
pp2		2.29	1.74	1.40			-0.55	<.001	-0.34	0.995
pp3	1.73	1.51	1.57	1.74	-0.21	0.801	0.05	0.66	0.17	0.096
pp4	1.59	1.59	1.36	1.63	0.00	0.501	-0.24	0.04	0.27	0.037
pp5	1.63	1.57	1.52	1.48	-0.07	0.671	-0.05	0.33	-0.04	0.615
pp7	1.96	1.79	1.53	1.94	-0.17	0.901	-0.26	0.01	0.41	0.001
pp8	1.33	1.63	1.52	1.76	0.30	0.008	-0.11	0.19	0.24	0.108
pp9	1.25	1.43	1.50	1.67	0.17	0.058	0.08	0.74	0.16	0.095
pp10	1.27	1.29	1.36	1.60	0.03	0.391	0.07	0.76	0.24	0.022
pp11	2.15	2.27			0.12	0.17				
pp12	1.54	1.74	1.64	2.18	0.20	0.051	-0.10	0.23	0.54	0.001
Overall effects										
				Mean difference[3]		.042		-.125		.182
				Cohen's d[3]		.131		.358		.411
				Sum *p*		3.552		3.04		1.989
				Overall *p*		0.139		0.02		<.001

[1] Participants 1 and 2 had no valid observations for phase A_1. Participant 6 dropped out of the study. Participant 11 had no valid observations for phase A_2 and B_2.

[2] Individual *p*-values below .1 were shaded grey.

[3] Note that the Mean differences and Cohen's *d* were not used in the randomization test.

Table S3. Mean Blue Light log10 Values and Mean Differences and p-Values for All Phases.

	A_1	B_1	A_2	B_2	B_1-A_1		A_2-B_1		B_2-A_2	
Participant[1]		***Mean***			M_d	*p*	M_d	*p*	M_d	*p*
pp1			0.77	1.04			-0.23	0.081	0.28	0.032
pp2			1.61	1.28			-0.60	0.001	-0.34	0.992
pp3	1.60	1.38	1.42	1.59	-0.22	0.824	0.04	0.667	0.17	0.111
pp4	1.48	1.48	1.22	1.51	0.00	0.515	-0.26	0.052	0.29	0.040
pp5	1.54	1.45	1.38	1.33	-0.10	0.739	-0.07	0.265	-0.05	0.640
pp7	1.84	1.64	1.39	1.80	-0.20	0.931	-0.26	0.016	0.42	0.001
pp8	1.20	1.47	1.41	1.68	0.28	0.017	-0.06	0.331	0.27	0.079
pp9	1.08	1.29	1.35	1.54	0.20	0.042	0.06	0.677	0.20	0.087
pp10	1.14	1.15	1.25	1.50	0.02	0.445	0.09	0.787	0.25	0.029
pp11	1.99	2.13			0.14	0.170				
pp12	1.38	1.61	1.51	2.05	0.23	0.040	-0.11	0.219	0.55	0.001
Overall Effects										
					Mean difference[3]	.039		-.137		.150
					Cohen's d[3]	.116		.366		.310
					Sum *p*	3.723		3.100		2.012
					Overall *p*	0.188		0.02		<.001

[1] Participants 1 and 2 had no valid observations for phase A_1. Participant 6 dropped out of the study. Participant 11 had no valid observations for phase A_2 and B_2.

[2] Individual p-values below .1 were shaded grey.

[3] Note that the Mean differences and Cohen's *d* were not used in the randomization test.

Table S4. Mean and median lux values per participant per phase

Participant	Lux Mean				Median			
	A1	B1	A2	B2	A1	B1	A2	B2
1		55,78	23,38	36,33		32,82	17,504	41,842
2		427,91	178,88	87,97		417,277	150,73	52,143
3	187,71	125,47	149,39	162,26	175,932	95,953	93,56	149,054
4	150,29	130,18	99,38	173,05	118,748	111,86	75,268	86,681
5	179,21	110,36	110,86	98,22	124,21	83,288	54,299	116,482
7	252,41	180,16	112,68	218	201,081	118,418	96,165	234,193
8	92,09	151,21	118,76	206,23	67,645	98,446	121,183	109,189
9	46,52	105,13	122,83	122,24	41,235	54,662	81,956	91,789
10	71,36	70,37	84,24	162,71	42,809	55,09	69,492	119,907
11	364,45	446,23			316,639	433,755		
12	129,18	162,5	153,6	312,73	107,689	137,732	132,463	278,389

Table S5. Results of the Randomization Tests for RGB in Morning, Afternoon and Evening

	morning		afternoon		evening	
	Sum_p	**p**	**Sum_p**	**p**	**Sum_p**	**p**
Blue						
A_1B_1	3.625	0.159	4.180	0.358	3.260	0.077
B_1A_2	4.452	0.277	3.117	0.019	3.449	0.115
A_2B_2	4.148	0.178	2.425	0.002	0.565	<.001
Green						
A_1B_1	3.646	0.165	4.087	0.319	3.447	0.114
B_1A_2	4.243	0.206	2.971	0.012	3.302	0.085
A_2B_2	3.937	0.124	2.285	0.001	0.693	<.001
Red						
A_1B_1	4.164	0.351	4.103	0.326	4.315	0.417
B_1A_2	5.183	0.578	3.055	0.016	4.999	0.715
A_2B_2	4.566	0.320	2.435	0.002	2.220	0.003

Table S6. Results of the Randomization Tests for RGB Apart for Fall-Winter and Winter-Spring

	Summer-Fall		Winter-Spring	
	Sum_p	**p**	**Sum_p**	**p**
Blue				
A1B1	2.974	0.954	0.702	0.001
B1A2	1.020	0.002	2.010	0.507
A2B2	1.822	0.048	0.205	<.001
Green				
A1B1	2.890	0.937	0.702	0.001
B1A2	1.125	0.003	1.882	0.422
A2B2	1.785	0.043	0.224	<.001
Red				
A1B1	3.109	0.974	1.126	0.015
B1A2	1.754	0.039	2.168	0.611
A2B2	1.962	0.073	0.489	0.002

Table A1. Estimated illuminance and Equivalent Daylight (D65) Illuminance (EDI) on the task/lap and at the eye of the free-floor standing luminaire

Phase		**Description**		**CCT**	**Task lighting ($E_{horizontal}$ on the lap)**		**Personal exposure ($E_{vertical}$ at the eye)**	
from	to	Intensity	Color		Illuminance (lx)	EDI_{mel} (lx)	Illuminance (lx)	EDI_{mel} (lx)
7:00 AM	7:30 AM	fast increase	cool white	6000K	0-1500	0-1100	0-510	0-370
7:30 AM	9:30 AM	slow increase	regular white	4000K	1500-2500	1100-1700	510-850	370-580
9:30 AM	3:30 PM	stable	regular white	4000K	2500	1700	850	580
3:30 PM	5:30 PM	slow dimming	warm white	3000K	2500-1500	1700-650	850-510	580-370
5:30 PM	7:30 PM	very slow dim	warm white	3000K	1500-750	650-400	510-255	370-185
7:30 PM	9:00 PM	very slow dim	very warm white	2500K	750-0	400-0	255-0	185-0

Note: Estimates based on measurements performed in a small white room without daylight, with a spectrometer fixed at the average estimated lap position to measure horizontal task illuminance and at the estimated eye position to measure vertical illuminance.

Table A2. Results on Illuminance, CCT and EDI_{mel} Spectrometer Values in Phase A_1 and B_1 for Kitchen, Bedroom and Living room measured vertically at the eye

	Illuminance (in lx)						**CCT (in K)**					
	Kitchen		**Bedroom**		**Living room**		**Kitchen**		**Bedroom**		**Living room**	
	A_1	**B_1**	**A_1**	**B_1**	**A_1**	**B_1**	**A_1**	**B_1**	**A_1**	**B_1**	**A_1**	**B_1**
pp1	41	777	41	194	16	540	5924	4465	4516	6704	3820	3152
pp2	195	818	24	919	3000	3550	3603	3909	4444	4456	4122	4104
pp3	847	724	3	2030	23	324	3149	3115	1600	6214	3507	4178
pp4	48	1280	26	1320	50	2140	5029	4180	4057	4620	4300	4218
pp5	48	577	2	2720	5	1300	3270	3884	1600	3424	2582	4181
pp7	114	710	47	766	82	575	5085	4337	4782	3498	4874	4247
pp8	43	982	53	2120	110	1360	2894	4115	5368	3521	4086	4193
pp9	37	745	15	2170	87	761	4386	4246	4814	3459	5653	4386
pp10	11	972	20	766	95	1210	3786	4140	4690	3465	5629	4453
pp11	133	528	3	105	35	548	4388	3621	1600	3357	6018	3350
pp12	8	584	11	1000	5	140	2661	3853	2429	3417	3594	2983
MeanDif		674		1261		813		-28		567		-431
Sig.		<.001		<.001		.03		0.532		0.169		0.88

Table A2. Continued

	EDI_{mel} (in lx)					
	Kitchen		**Bedroom**		**Living room**	
	A_1	B_1	A_1	B_1	A_1	B_1
pp1	40	556	32	195	27	263
pp2	121	520	19	659	2131	2496
pp3	444	378	2	1829	18	192
pp4	41	853	18	964	36	1413
pp5	28	371	0	1377	1	854
pp7	95	489	38	430	69	390
pp8	20	634	47	1165	72	892
pp9	25	558	13	1172	81	528
pp10	7	631	16	416	77	860
pp11	102	319	3	56	34	299
pp12	54	321	1	54	20	248
		356		653		599
		0.002		0.004		<0.001

Figure A3: boxplots of sleep variables (figures 1-7)

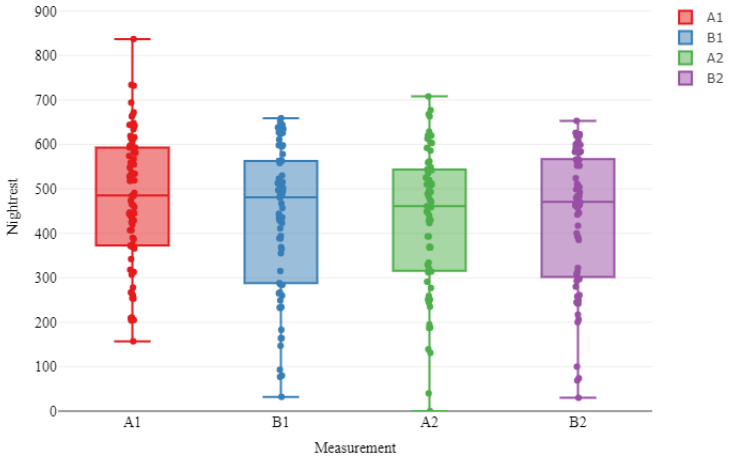

Figure 1. Night rest in minutes

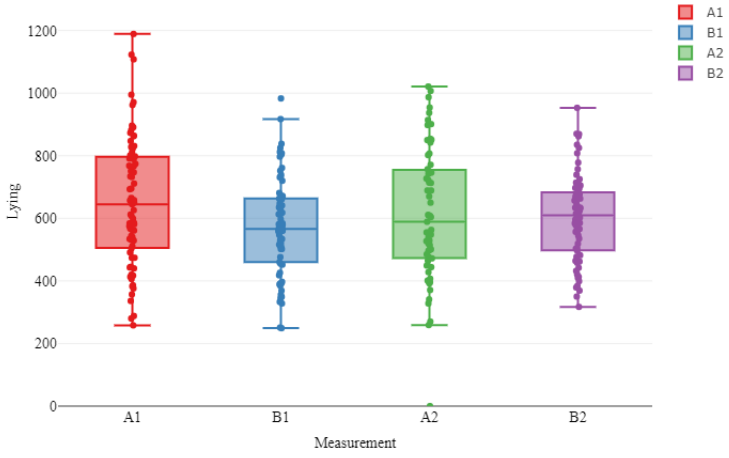

Figure 2. Minutes lying in bed at night

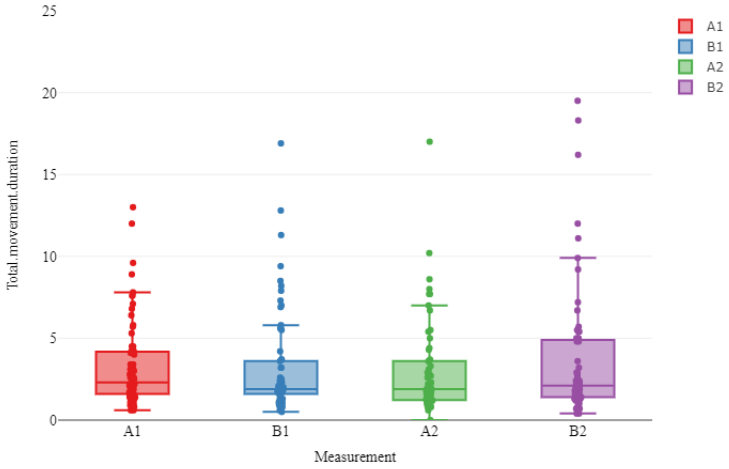

Figure 3. Total movement duration at night

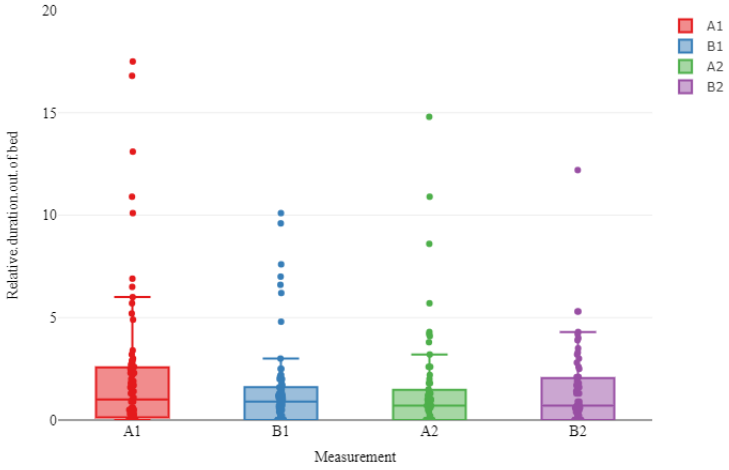

Figure 4. Relative duration out of bed at night

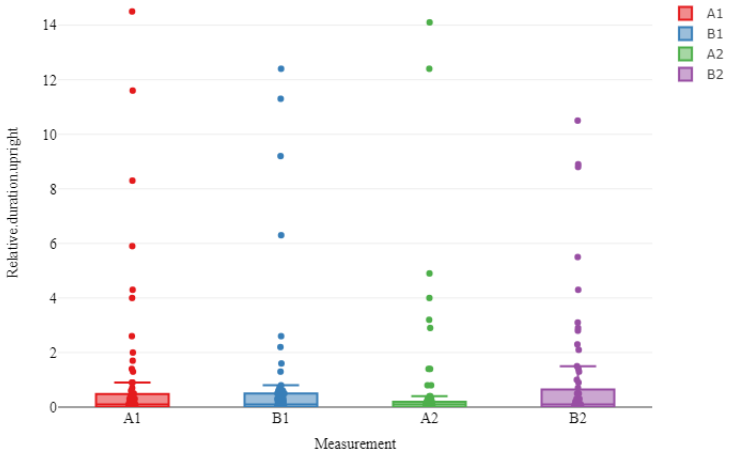

Figure 5. Relative duration upright at night

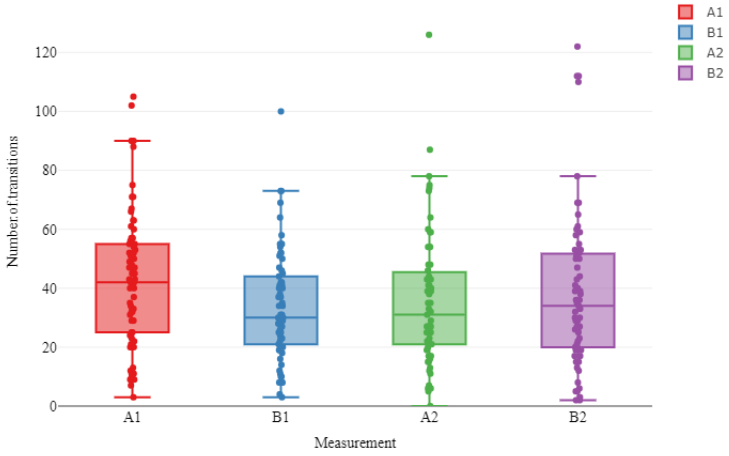

Figure 6. Number of transitis at night

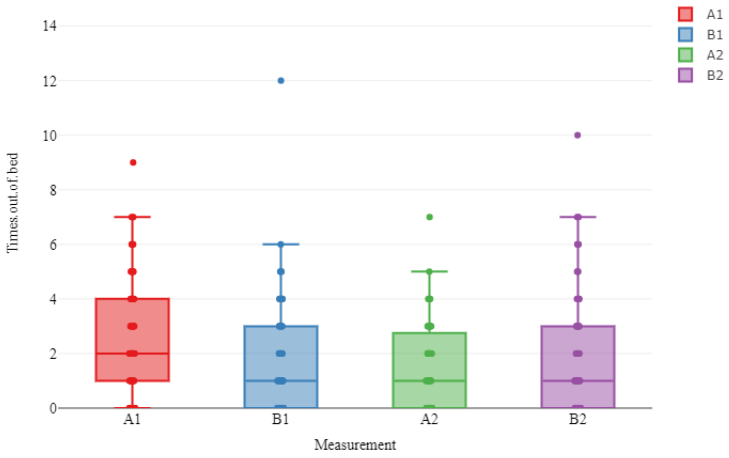

Figure 7. Times out of bed at night

Table A4. Results of the Randomization Tests at Group Level for the Secondary Sleep Variables in the night

	A1	B1	A2	B2	A1 - B1		B1 -A2		A2 - B2	
						p_{S^3Sobs}		p_{S^3Sobs}		p_{S^3Sobs}
	Median				S_{obs}[1]		S_{obs}		S_{obs}	
Lying	645	566	589	610	6.39	0.821	5.5	0.705	4.98	0.491
Movement	2.3	1.9	1.9	2.1	3.92	0.050	4.59	0.329	5.79	0.804
Times out of bed	2	1	1	1	5.73	0.594	7.59	0.998	7.67	0.999
Duration out of bed	1	0.9	0.7	0.7	5.618	0.548	6.61	0.970	6.22	0.907
Duration upright	0.1	0.1	0.1	0.1	6.69	0.884	7.44	0.997	6.83	0.978
Transitions	42	30	31	34	4.32	0.110	4.03	0.147	4.33	0.233

[1] S_{obs} is the sum of all *p*-values of the participants

Table A5 Mean and Standard Deviation for the Psychological Measures

	T0		A1		B1		A2		B2	
	M	**sd**	**M**	**sd**	**M**	**sd**	**M**	**sd**	**M**	**sd**
GDS-15	4.73	3.52	5.36	3.96	4.09	3.75	6.30	4.42	5.50	4.22
HADS-A	5.18	4.98	4.45	4.68	3.45	4.80	4.80	4.24	4.80	5.16
CMAI	47.45	6.15	49.18	10.55	42.27	5.62	45.80	7.44	45.20	8.35

SUMMARY

Dementia is a profound disease with a huge impact on the people with dementia themselves, their environment and society. Most persons with dementia prefer to live independently for as long as possible and the government also favours so-called ageing-in-place over institutionalisation. However, the progressive course of the disease is often accompanied by sleep problems and reduced psychological well-being, subsequently increasing the risk of transition to a care setting. Dementia intensifies the ageing process of the brain and the eye. As a result, the biological clock is not properly stimulated. Via this internal clock, light with the right characteristics can have a positive effect on their sleep pattern and psychological well-being. This PhD project investigated the impact of an off-the-shelf dynamic light system on sleep patterns, disinhibited behaviour, and psychological well-being of people with dementia in a clinical and home setting.

Studying light interventions in people with dementia living at home is difficult and therefore extremely rare. The heterogeneity of the population makes it difficult and less suitable to conduct a randomized controlled trial (RCT) in which a substantial number of participants would be assigned to control and intervention groups for comparison purposes. Instead, a suitable study design for our study purpose would need to consider that living circumstances, daily routines, the type of dementia, time since diagnosis and other personal characteristics differ per participant.

We performed two longitudinal studies, one in a clinical setting and one in a home setting, using a real-life Single Case Experimental Design (SCED) to establish the effectiveness of a dynamic light system in everyday situations and over a prolonged time period in people with dementia. A SCED, in which a small number of participants undergo repeated measurements during intermittent control and intervention phases (ABAB), proved in our studies to be applicable and suitable to conduct studies on the impact of a light intervention in people with dementia. Using personal wearables and sensors allowed us to monitor variables per person continuously, and as accurately as possible. This real-life study design thus combined high ecological and internal validity.

Our studies showed that a transportable dynamic light system was able to significantly increase exposure to light in both the clinical setting and home setting. In the clinical setting, exposure to dynamic light demonstrated significant effects on various sleep pattern variables, such as the frequency of night-time bed wandering and minutes of night rest. Furthermore, non-parametric testing showed a decreased severity of neuropsychiatric symptoms after exposure to dynamic light. Disinhibited behaviour decreased significantly.

In the home setting, the results were analysed by randomisation testing. This demonstrated a trend of improvements, although non-significant, in sleep-pattern variables using dynamic light. On psychological well-being, the overall trend from the beginning to the end of the experiment showed significant decreases in agitation and depression. It is a notable finding that improvements in psychological well-being occurred without a parallel significant improvement in sleep patterns. This suggests that light may have positive effects through multiple pathways: light may exert part of its impact via the internal biological clock, but light could also have positive effects on psychological well-being via other pathways in the brain, circumventing the clock. It is, therefore, promising to increase light exposure even in the absence of sleep disturbances.

The light intensity differences between intervention and control conditions were larger in the clinical setting than in the home setting. Possible explanations are that participants in the clinical setting spent less time outside than participants still living at home. Besides, indoor circumstances in the clinical setting were very dark, resulting in lower light exposures in their regular daily living conditions compared to participants in the home setting. Furthermore, the actual contribution of a lighting intervention also depends on the characteristics of the selected installation. In the clinical setting we used a different installation than in the home setting.

In conclusion, the findings of both studies suggest that a transportable light system is a suitable and promising technological intervention to support people with dementia and can improve sleep and psychological well-being in people with dementia in a clinical and home setting. A dynamic light system may particularly achieve more effectiveness on the sleep pattern in homes with dark interiors or few windows and for participants who go outside infrequently. Moreover, the added value of the light system seems most prominent in darker seasons, such as fall and winter, and in the afternoon and evening.

Despite their promising benefits, the use of supportive technology by persons with dementia is currently still limited. For the successful implementation of technological innovations intended to support people with dementia, scientific research in the home setting is essential. It is promising that people with dementia are increasingly involved in the use and development of supportive technologies, but to date, they are still mostly involved only in the evaluative phase, making their role as informant in the design process quite limited. Involving people with dementia in the development, testing and implementation of supportive technology can provide insights into the variety of needs, wishes and abilities of people with dementia and can ultimately lead to a more empathic understanding. Participants' reasons for participating in our study were to be useful and involved in research, to contribute to a better quality of life for future people with dementia, and to be able to give their opinion and share experiences. They also reported about the preferred characteristics of the dynamic light systems.

This PhD project provided valuable and timely insights into how a transportable dynamic light system can be supportive for persons with dementia, especially in certain seasons and for those who do not spend much time outside in natural daylight. Moreover, it demonstrates that, in spite of all its challenges, intensive, longitudinal, scientifically sound research with this target group is feasible and can be rewarding for all parties involved.

SAMENVATTING

Dementie is een ingrijpende ziekte met een enorme impact op de mensen met dementie zelf, hun omgeving en de samenleving. De meeste mensen met dementie willen zo lang mogelijk zelfstandig blijven wonen en ook de overheid geeft de voorkeur aan het zogenaamde “ageing-in-place” boven opname in een instelling. Het progressieve verloop van de ziekte gaat echter vaak gepaard met slaapproblemen en een verminderd psychologisch welzijn, waardoor het risico op een overgang naar een zorginstelling toeneemt. Dementie versterkt het verouderingsproces van de hersenen en het oog. Hierdoor wordt de biologische klok niet goed gestimuleerd. Via deze interne klok kan licht met de juiste eigenschappen een positief effect hebben op hun slaappatroon en psychologisch welzijn. Dit PhD-project onderzocht de impact van een kant-en-klaar dynamisch lichtsysteem op slaappatronen, ontremd gedrag en psychologisch welzijn van mensen met dementie in een klinische en thuissituatie.

Het bestuderen van lichtinterventies bij mensen met dementie die thuis wonen is moeilijk en daarom uiterst zeldzaam. De heterogeniteit van de populatie maakt het moeilijk en minder geschikt om een gerandomiseerde gecontroleerde trial (RCT) uit te voeren waarin een aanzienlijk aantal deelnemers ter vergelijking aan controle- en interventiegroepen zou worden toegewezen. In plaats daarvan zou een geschikte studieopzet voor ons doel rekening moeten houden met het feit dat de levensomstandigheden, dagelijkse routines, het type dementie, de tijd sinds de diagnose en andere persoonlijke kenmerken per deelnemer verschillen.

Wij hebben twee longitudinale studies uitgevoerd, één in een klinische setting en één in een thuissituatie, met behulp van een real-life Single Case Experimental Design (SCED) om de effectiviteit van een dynamisch lichtsysteem vast te stellen in alledaagse situaties en gedurende een langere periode bij mensen met dementie. Een SCED, waarbij een klein aantal deelnemers herhaalde metingen ondergaat tijdens afwisselende controle- en interventiefasen (ABAB), bleek in onze studies toepasbaar en geschikt om studies uit te voeren naar het effect van een lichtinterventie bij mensen met dementie. Door het gebruik van persoonlijke wearables en sensoren konden we variabelen per persoon continu en zo nauwkeurig mogelijk monitoren. Deze real-life studieopzet combineerde dus een hoge ecologische en interne validiteit.

Onze studies toonden aan dat een verplaatsbaar dynamisch lichtsysteem in staat was om de blootstelling aan licht aanzienlijk te verhogen, zowel in de klinische setting als in de thuissituatie. In de klinische setting vertoonde blootstelling aan dynamisch licht significante effecten op verschillende slaapvariabelen, zoals de frequentie van nachtelijk dwalen en het aantal minuten nachtrust. Bovendien bleek uit niet-parametrische tests dat de ernst van neuropsychiatrische symptomen afnam na blootstelling aan dynamisch licht. Ontremd gedrag nam aanzienlijk af.

In de thuissituatie werden de resultaten geanalyseerd door middel van randomisatietests. Hieruit bleek een trend van verbeteringen, hoewel niet-significant, in de variabelen van het slaappatroon bij gebruik van dynamisch licht. Wat psychologisch welzijn betreft, toonde de algemene trend van het begin tot het einde van het experiment significante dalingen in agitatie en depressie. Het is een opmerkelijke bevinding dat verbeteringen in psychologisch welzijn optraden zonder een parallelle significante verbetering in slaappatronen. Dit suggereert dat licht positieve effecten kan hebben via verschillende wegen: licht kan een deel van zijn invloed uitoefenen via de interne biologische klok, maar licht kan ook positieve effecten hebben op psychologisch welzijn via andere wegen in de hersenen, waarbij de klok wordt omzeild. Het is daarom veelbelovend om de blootstelling aan licht te verhogen, zelfs als er geen sprake is van slaapstoornissen.

De verschillen in lichtintensiteit tussen interventie- en controleconditie waren groter in de klinische setting dan in de thuissituatie. Mogelijke verklaringen zijn dat deelnemers in de klinische setting minder tijd buiten doorbrachten dan deelnemers die nog thuis woonden. Bovendien waren de omstandigheden binnenshuis in de klinische setting erg donker, waardoor de blootstelling aan licht in hun normale dagelijkse leefomstandigheden lager was dan bij deelnemers in de thuissituatie. Bovendien hangt de werkelijke bijdrage van een lichtinterventie ook af van de kenmerken van de gekozen installatie. In de klinische setting hebben wij een andere installatie gebruikt dan in de thuissituatie.

Concluderend suggereren de bevindingen van beide studies dat een verplaatsbaar lichtsysteem een geschikte en veelbelovende technologische interventie is om mensen met dementie te ondersteunen en de slaap en het psychologisch welzijn bij mensen met dementie in een klinische en thuissituatie kan verbeteren. Een dynamisch lichtsysteem kan met name meer effect hebben op het slaappatroon in woningen met een donker interieur of weinig ramen en voor deelnemers die weinig buiten komen. Bovendien lijkt de toegevoegde waarde van het lichtsysteem het grootst in donkere seizoenen, zoals herfst en winter, en in de namiddag en avond.

Ondanks de veelbelovende voordelen is het gebruik van ondersteunende technologie door mensen met dementie momenteel nog beperkt. Voor een succesvolle toepassing van technologische innovaties ter ondersteuning van mensen met dementie is wetenschappelijk onderzoek in de thuissituatie essentieel. Het is veelbelovend dat mensen met dementie steeds meer betrokken worden bij het gebruik en de ontwikkeling van ondersteunende technologieën, maar tot op heden worden zij meestal alleen betrokken bij de evaluatiefase, waardoor hun rol als informant in het ontwerpproces vrij beperkt is. Mensen met dementie betrekken bij het ontwikkelen, testen en implementeren van ondersteunende technologie kan inzicht geven in de verschillende behoeften, wensen en mogelijkheden van mensen

met dementie en kan uiteindelijk leiden tot een meer empathisch begrip. De redenen van de deelnemers om deel te nemen aan ons onderzoek waren: nuttig en betrokken te zijn bij het onderzoek, bij te dragen aan een betere levenskwaliteit voor toekomstige mensen met dementie, hun mening te kunnen geven en ervaringen te delen. Ze evalueerden ook wat voor hen belangrijke eigenschappen waren van de dynamische lichtsystemen.

Dit PhD-project leverde waardevolle en actuele inzichten op in hoe een verplaatsbaar dynamisch lichtsysteem ondersteunend kan zijn voor mensen met dementie, vooral in bepaalde seizoenen en voor degenen die niet veel tijd buiten in natuurlijk daglicht doorbrengen. Bovendien toont het aan dat, ondanks alle uitdagingen, intensief, longitudinaal, wetenschappelijk verantwoord onderzoek met deze doelgroep haalbaar is en voor alle betrokken partijen lonend kan zijn.

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The future is in our present hands
Let's reach right in
Let's understand
If you want it you got it
You just got to believe
Believe in yourself
-Lenny Kravitz-

Mijn eerste woorden van dank gaan natuurlijk uit naar de deelnemers aan mijn onderzoek, zonder wie het hele project niet mogelijk was geweest. Tijdens de voorgesprekken en de vele ontmoetingen bij jullie thuis, heb ik jullie allen leren kennen. Wie jullie zijn, hoe jullie leven eruit zag, en wie jullie vroeger waren. Ik heb genoten van alle levensverhalen en ben vereerd dat ik, in vaak de meest kwetsbare periode in jullie leven, een stukje met jullie mee mocht lopen. Ik ben dankbaar voor het contact, dat vaak verder ging dan een 'standaard' contact tussen een onderzoeker en onderzoeksdeelnemer. Ik heb vele kopjes koffie en lekkernijen gekregen, bakrecepten en ansichtkaartjes uitgewisseld. Maar ook met jullie gelachen en gehuild. Helaas is een aantal deelnemers na hun deelname overleden. Ik denk met warme gevoelens aan hen terug. Met diepe bewondering en respect ben ik getuige geweest van verschillende vormen van onvoorwaardelijke liefde tussen twee mensen. Voor mij als systeemtherapeut hebben jullie mij ook vanuit dat oogpunt veel geleerd. Ik hoop dat dit werk bijdraagt aan jullie welbevinden. Een speciaal woord van dank gaat uit naar Florentine, die mij de eer verschafte om, naast deelnemer van het onderzoek samen met haar inmiddels overleden man Coen, mijn paranimf te zijn. Hier was geen twijfel over mogelijk Florentine, jullie hebben een plek in mijn hart.

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Ellen van Lieshout - van Dal

Eindhoven, juli 2023

ABOUT THE AUTHOR

Curriculum Vitae

Ellen van Lieshout – van Dal was born on April 29th, 1977, in Eindhoven, the Netherlands. After finishing secondary education at the Eckart College in Eindhoven, she studied Social Studies for one year before switching to Health Sciences at Maastricht University. After attaining her master's degree in Mental Health Sciences in 2000, she started working in several health care institutions. She was registered as Health Care Psychologist in 2004 and worked as Health Care Psychologist at GGz Breburg Psychiatric Hospital for over ten years. During these years she became a family and relationship therapist, treatment manager and founded a clinical and daytime treatment facility for young adults. She was keen on including family in every treatment. In 2014 she started the training as clinical psychologist at GGzE, psychiatric hospital in Eindhoven, and worked in various units in this institution. During the research track of the clinical psychology training, she met prof. dr. Inge Bongers and dr. ing. Liselore Snaphaan. They helped shape her research ambitions as a science practitioner and encouraged her to upscale the research to a PhD track. A few years later, prof. dr. Yvonne de Kort joined the team as PhD supervisor. After finishing the clinical psychology track in 2018, Ellen combined research with clinical work on a ward for adolescents with orthopsychiatric problems. She currently combines this clinical work with adolescents at GGzE, Eindhoven, with working as a trainer, supervisor and learning therapist for future therapists, registrated by the Dutch Association for Relationship and Family Therapy.

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