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DESIGNING WITH AND FOR PEOPLE WITH DEMENTIA
Wellbeing, Empowerment and Happiness

Converting wandering behaviour into a guided activity

a case study of co-designing with People Living with Dementia based on theoretical models

Gubing Wang, Armagan Albayrak, Tischa J. M. van der Cammen

g.wang-2@tudelft.nl, A.Albayrak@tudelft.nl,
Faculty of Industrial Design Engineering, Delft University of Technology, Delft, The Netherlands
T.J.M.vanderCammen@tudelft.nl, Faculty of Industrial Design Engineering, Delft University of Technology, Delft; Section of Geriatric Medicine, Department of Internal Medicine,
Erasmus University Medical Centre, Rotterdam, The Netherlands

Abstract: For People Living with Dementia (PLwD), wandering behaviour can cause undesired consequences, such as falling, getting lost or even fatalities. For caregivers, taking care of PLwD with wandering behaviours is burdensome. If not intervened early, some wandering behaviours will escalate into crisis events. This design research aims to explore how to convert the wandering behaviour to a guided activity with the minimum input from caregivers by intervening early, that is, engaging PLwD, to avoid potential escalations. Based on Need-driven Dementia-compromised Behaviour (NDB) model, Crisis Development model and via a co-design approach, we developed De-light. De-light is a set of interactive sticks enhanced by light, audio and tactile experiences. Based on the degree of wandering behaviours of PLwD, De-light can be placed by the caregiver in a safe and suitable area in the nursing home to provide a controlled setting for guiding PLwD to perform physical activity. Our design research implies the possibilities of applying NDB model, Crisis Development model, and co-design approach in designing for the wandering behaviours for PLwD.

Keywords: *Nursing Home; Behavioural and Psychological Symptoms of Dementia; Physical Activity; Dementia Care*

1. Introduction

Wandering, in People Living with Dementia (PLwD), is a common behaviour that can cause a great risk for the person and has been described as one of the most challenging behaviours to manage (Lai, et al, 2003). Moreover, wandering behaviour can cause undesired consequences, such as falling, and in the worst-case scenario, fatalities (Algase, et al, 1996). Professional caregivers in nursing homes, which are referred to as caregivers in this article, have to take care of several PLwD during their shifts, and have reported burnouts when caring for PLwD with wandering behaviours (Yang, 2017).

According to the Need-driven Dementia-compromised Behaviour (NDB) model, the factors contributing to challenging behaviours in PLwD like wandering, physical aggression and vocalization can be divided into background and proximal factors (see Fig. 1) (Algase, et al, 1996). Background factors mentioned in the model are relatively intrinsic thus very difficult to change. Proximal factors, on the contrary, can be interfered with for managing challenging behaviours, and can be categorized into personal factors, factors in the physical environment and factors in the social environment. The personal factors include emotions, functional performances and physiological needs of the PLwD. One common need for PLwD with wandering behaviours is that they are constantly looking for stimulations from the environment (van der Plaats, 2009). The factors in the physical environment contains macro components, which are the overall settings including layout and routines in the nursing home; and micro components, which are physical stimuli, such as light and sound. The factors in the social environment encompasses all interactions with people, which include caregiver stability, ward ambience, and caregiver demeanours.

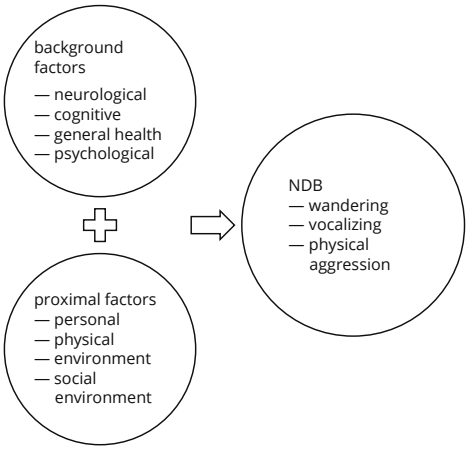

Figure 1 Need-driven Dementia-compromised Behaviour (NDB) model (reproduced based on Algase et al., 1996). The combination of background factors and proximal factors will generate Need-driven Dementia-compromised Behaviours (NDB).

The current methods for dealing with PLwD with wandering behaviours in the nursing home focus mainly on avoiding wandering behaviour, trying to control it with restrictions or applying precautions. For instance, putting warning signs on the door, hiding the doors or using monitoring systems to locate PLwD and then interrupt the behaviour (see Fig. 2).

Figure 2 Current methods used in the nursing homes for managing wandering behaviours in PLwD, which mainly discourage wandering.

According to the Crisis Development model (Crisisontwikkelingsmodel in Dutch), wandering behaviour is a sign of fear of losing control and of increasing in stress in PLwD (see Fig. 3) (Voskes, et al, 2011). This model divided the degree of tension in PLwD into five phases along with time. Specifically, in phase 0, PLwD perform usual activities and do not exhibit challenging behaviours. In phase 1, as their stress levels increase, wandering behaviours are observed in PLwD. If there is no intervention at this stage, the tension in PLwD will keep increasing to phase 2, at which PLwD is under high stress and not fully in control. If there is still no intervention applied, the stress in PLwD will keep increasing to phase 3, at which their control is completely gone and crisis events arise (e.g. physical violence). It takes time and effort for caregivers to let the PLwD at phase 3 return to the relaxed phase (phase 4). Simply limiting PLwD from wandering could make their behaviours even worse. Instead, intervening early, that is, engaging PLwD, could be helpful to prevent PLwD and their caregivers from experiencing crisis events. However, the caregivers are usually occupied with several PLwD during their shifts, so intervening to prevent escalation of wandering behaviours is not immediately possible most of the times.

Several studies have shown that doing exercise is beneficial for the emotional and physical wellbeing of PLwD (Brett, et al, 2016; Chen, et al, 2017; Williams, et al, 2008). As the duration of care received per PLwD in the nursing home is expected to decrease in the future (Eggink, Ras, & Woittiez, 2017), there is a growing need for initiatives that stimulate physical activities that do not rely heavily on the caregivers.

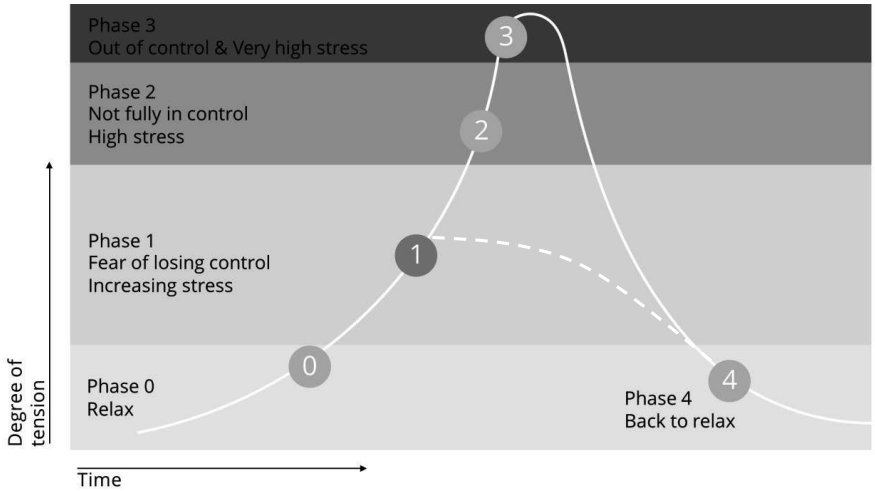

Figure 3 **Crisis Development model (Crisisontwikkelingsmodel in Dutch, based on Voskes, et al, 2011). Wandering behaviours are commonly seen in Phase 1. The dotted line indicates the ideal transition from wandering behaviours to the relax state for PLwD.**

2. Objective

The aim of this design research is to turn the wandering behaviour into a guided activity for PLwD with minimal input from caregivers by intervening early. Referring to the Crisis Development model (see Fig. 3), the design intervention aims to create a smooth direct transition from phase 1 to phase 4 for the PLwD, hence later stages of crisis (phase 2 and 3) are avoided and thus it takes less time and effort for caregivers to calm PLwD down. Both PLwD with wandering behaviours and their caregivers are the users of our design intervention.

3. Methods

In the early research phase, we used video coding to analyse the wandering behaviours of PLwD and the according behaviours of the caregiver. It helped us gain a deeper understanding about the context quickly. In the design phase, we carried out a co-design session with two PLwD and a caregiver. Through this session, we identified what PLwD like and do not like as well as the needs and wishes of caregivers, and gained real-life experience in interacting with PLwD with wandering behaviours. In addition, we followed the recommendations on capability considerations for PLwD to ensure the design intervention will fit with the capability levels of PLwD.

3.1 Video coding

Two videos were taken of one PLwD in two different scenarios at the nursing home Zorggroep Elde in the Netherlands under ethics approval and informed consent from the caregivers and the legal representatives of the PLwD. One video was taken when the PLwD with wandering behaviour staying in his own bedroom, and the other video was taken when the PLwD staying in the dining room and the caregiver making sure the PLwD would not wander to the kitchen and to other PLwD. Firstly, four Master students (Industrial Design Engineering, Delft University of Technology) coded these videos independently by recording behaviours of PLwD and caregivers in a list with timestamps, then all these lists were compared, and summarized when consensus was reached after a discussion with the first author GW (the anonymized video coding is available upon request).

From the video coding, we found that this PLwD easily lost attention on the activity that he was currently doing and there was no activity that could keep him engaged for over half a minute when he was staying alone in his bedroom. In contrast, he wandered less in the dining room, as the caregiver tried to attract his attention by using a soft football every time he wanted to wander off to the kitchen and to other PLwD. Specifically, the caregiver played with the football in front of the PLwD, and invited him to touch the ball and play with her. When the caregiver was playing the ball, the sound generated as the ball bounced on the floor and the movement of the ball attracted the attention from the PLwD. When the PLwD touched the ball, he began to squeeze and hold the ball close to him and examined it. He then throwed the ball back to the caregiver, and the caregiver throwed the ball back to him. This playful throwing lasted for seven to eight rounds, then the PLwD lost attention and started to wander again. Then the caregiver tried to catch the attention of the PLwD by having a "conversation" with him. Even though what the PLwD said was not comprehensible, the caregiver nodded and replied with simple words as if she understood what the PLwD was talking about. In this way, the PLwD engaged in this "conversation" for a while and then wandered again. The caregiver was fully occupied in attracting attention of this PLwD with using these two methods (soft football and "conversation") interchangeably throughout the video, and she had no interactions with other residents throughout the video.

We therefore came up with the following hypothesis: 1) physical stimulus (e.g. light, sound, and texture) can attract attention of PLwD; 2) interactive elements can prolong the attention time of PLwD.

3.2 Co-design session

The co-design session was also carried out at the nursing home Zorggroep Elde in the Netherlands under ethics approval and informed consent from the caregivers and the legal representatives of the PLwD. The co-design session started at 5 o'clock in the afternoon and lasted for one hour. Two PLwD and a professional caregiver participated in this session.

This session was organized by following the tools and recommendations for co-designing with People with Dementia (Hendriks, et al, 2013; Wang, et al, 2019). Specifically, the location was selected to be the nursing home as it offers a quiet and familiar environment for PLwD and minimizes travelling for the PLwD and the caregiver. The researchers (GW and Master students) had been flexible, empathic, patient, valuing different forms of participation, and presenting ethical concerns throughout the session. In addition, the researchers were well-informed about the daily life of PLwD before the session by the previous visit. The recruitment was done via direct contact with potential participants, and people who have experience with caring for PLwD were also recruited. The recruitment was kept open throughout the project. The group size in the session was kept to be smaller than a usual focus group session, and informal breaks were allowed in the session.

Since the PLwD participants are in the moderate to severe stage of dementia, we also chose from the recommendations that apply to these stages. Specifically, we brought probes and observed the reactions of PLwD towards these probes; we used tangible materials and auditory stimuli; we considered the physical limitations (e.g. eyesight, hearing) of the PLwD by asking the caregiver if they have any sensory impairments; we paid attention to their facial expressions and body language towards the probes, and also let the caregivers act as interpreters for these non-verbal behaviours while being aware of the opinions of the caregivers involved; we encouraged caregivers to support PLwD by giving physical instructions such as touching and supported physical movements; we talked along and helped PLwD like a caregiver would do instead of taking notes; and in general, we learned person-centred care principles and applied these principles throughout the session.

In the co-design session, we aimed to know what kind of physical stimuli and interactive elements PLwD like and do not like and what are the needs and wishes of the caregiver. In terms of the stimuli, we placed them near the PLwD to see if they could notice these stimuli. The stimuli included a Bluetooth speaker playing soothing music, a green LED chain with constant light and another green LED chain with flashing light. As for the interactive element, we provided them a ball (more interactive: lights up when being touched) and a small square speaker (less interactive: no reaction when being touched), then we observed the PLwD and counted the time they spent on each object.

We have gained valuable insights from the co-design session. We found that the PLwD had very narrow visual fields and were too focused on their private area to notice the outside stimuli without the guidance from caregivers, they did not have an observable response to the music, and there was no significant difference between the time they spent on the ball and the speaker. However: 1. PLwD are more likely to respond to the human voice (e.g. instructions from caregivers). 2. PLwD can notice things outside their visual field if guided by caregivers. The caregiver wanted the design intervention to be safe, easy-to-use, quick to set up, and can let her easily identify if it is broken.

3.3 Capability considerations

Since wandering behaviour is defined as one symptom of Behavioural and Psychological Symptoms of Dementia (BPSD) in the medical field, we position our design intervention to be considered as a type of non-pharmacological interventions for PLwD which could be evaluated for its effectiveness in reducing wandering behaviours in PLwD. Previous findings recommend that non-pharmacological interventions should be designed with the capabilities of PwD in mind under the guidance of ergonomics (Wang, et al, 2018). Therefore, we followed the design recommendations for non-pharmacological interventions treating BPSD (Wang, et al, 2019).

Specifically, in the sensory-oriented aspect, we ensured the sound sources to be located close and by the sides of PLwD when they interact with the design intervention; low-frequency sound was used; the light source was determined to change its brightness gradually; the emitted light was designed to be diffused; reflecting surfaces were avoided; the wavelength of the light was chosen to be from 570 nm to 620 nm. Concerning the cognition-oriented aspect, we embedded auditory and visual prompts in the design intervention to attract attention from PLwD; the guided activity that the design intervention intends to initiate was decided to involve no planning, sequencing and multitasking from the PLwD. Regarding the movement-oriented aspect, the intended guided activity was designed to only involve movement with low intensity and slow rhythm from the PLwD.

4. The design

In light of the NDB model, Crisis Development model, video coding, co-design session and design recommendations for capability considerations, we came up with the final design concept – De-light (see Fig. 4).

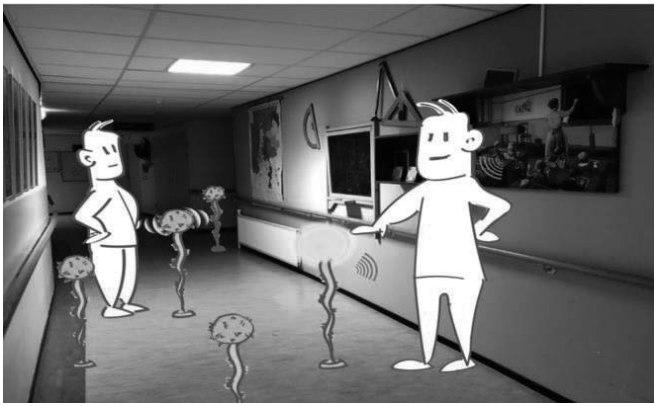

Figure 4 The design concept of De-light, which is designed to convert wandering behaviours into a guided physical activity.

The interaction details of De-light are demonstrated by the prototype (see Fig. 5), and the numbers in the figure correspond to the numbers in the text describing the interaction details. The details are as follows:

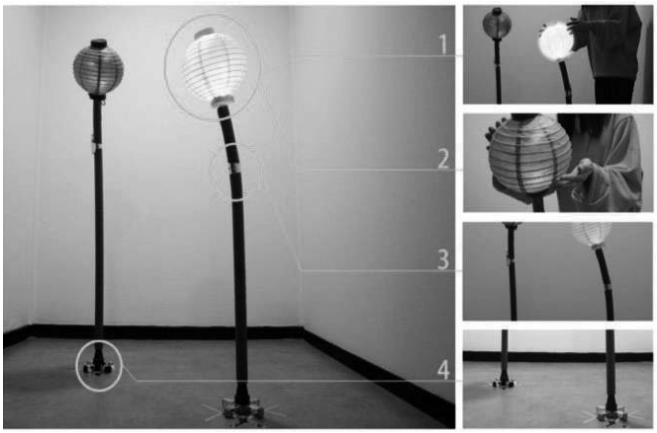

Figure 5 De-light prototypes and interaction details. The four small images illustrate the four enlarged interaction details of the prototype. The numbers on the image correspond to the numbers in the text.

1. The De-light only has an On/Off button so that it is easy-to-use for caregivers. When turned on, the De-light automatically lightens by detecting the proximity of PLwD. The sphere will light up when it detects a PLwD is in proximity to attract his/her attention, thereby triggers the subsequent interactions between PLwD and De-light. The caregiver immediately knows De-light is broken if it does not lighten up when switched on.
2. The glowing sphere on the top of the stick is soft and elastic to invite PLwD to touch and cuddle it. By touching the sphere, De-light can automatically give verbal responses (e.g. "Hey, I like your warm hands!"). De-light also softly asks questions (e.g. "Hello, how are you today?") to maintain the attention of the PLwD until the PLwD stops touching it for five minutes. The light goes off when the PLwD leaves.
3. The stick part is soft and flexible, so that De-light behaves like a tilting doll when bended by the PLwD, thereby creating a playful movement interaction with the PLwD; this could also increase the number of ways that PLwD interact with the De-light.
4. The bottom of De-light is moveable, and De-light has a light weight, yet is stable on the floor when pushed and pulled, so caregivers can place appropriate numbers of De-Lights quickly and easily in the corridor or other environments in the ward as needed.

As mentioned in the NDB model, the physical environmental factors can be interfered with by the macro components and the micro components (Algase, et al, 1996). De-light takes both macro and micro components into consideration. For the macro components, De-light allows caregivers to personalize and customize the layout of the environment for the PLwD, specifically, caregivers can place different numbers of De-lights in a safe and suitable area in the nursing home (e.g. corridors, living room, individual room of PLwD) to form an interactive environment for PLwD as needed; for the micro components, De-light uses lights, sounds and tactile feedbacks as interactive means for PLwD to satisfy their needs in seeking stimulation. Regarding social environmental factors, the guidance of caregivers on PLwD is an essential part of using De-light, while De-light is designed to be involving caregivers as little as possible. According to the Crisis Development model, De-light should be used when the PLwD starts the wandering behaviour.

From the video coding and co-design session, PLwD easily lose attention in the same object or activity quickly, they respond to human voices better than music, and their attention can be guided by caregivers. However, caregivers have to take care of several PLwD at the same time, thus they do not have full attention to guide one PLwD throughout their shifts. De-light should be easy to set up, and only requires the caregiver to initiate and end the activity. By setting a series of De-light in the environment, when the PLwD loses interest in one De-light, he/she can be attracted to the next De-light. Once the activity is initiated, the interactive elements in De-light will keep PLwD engaged. Therefore, De-light allows PLwD to vent their stress and energy by engaging them via a series of interactions without dramatically increasing the workload of caregivers.

In the intended use scenario, when a caregiver empirically judges that a PLwD starts wandering around, the caregiver will set a few De-lights in an area in the ward where he/she finds it safe and suitable. Then he/she will guide the PLwD to the De-lights environment and guide the PLwD to interact with De-lights for a couple of minutes. After the activity is initiated, the interactive elements in the De-light will keep PLwD engaged with minimal assistance from caregivers. When the energy and stress of PLwD are fully vented by playing with De-lights, which is also judged by the caregiver, the caregiver will guide the PLwD moving out of the De-lights environment to let PLwD rest and relax. De-light encourages physical activities in PLwD, and since the PLwD will be around the De-light environment during the intervention, he/she will "wander" in the safe environment set by the caregiver. The caregivers do not have to constantly monitor the wandering of the PLwD, thus can better divide attention to every PLwD within his/her duties. The stress and energy in PLwD are also vented in time so that potential crisis events could be avoided (e.g. PLwD becomes physically aggressive). The expected benefits of using De-light are summarized in Fig. 6.

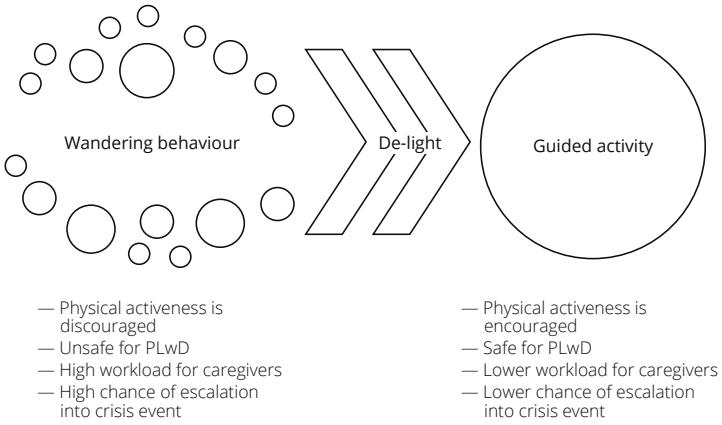

Figure 6 The expected benefits of De-light in the intended use scenario for wandering behaviour

5. Discussion

By manipulating the macro and micro components in the physical environment, together with minimal assistance from the social environment (caregivers), De-light could potentially encourage PLwD with wandering behaviours to vent their stress and energy in a controllable way. Served as a set of interactive stimuli, De-light can positively solve the needs of PLwD in constantly looking for stimulation. Instead of restricting PLwD in a closed room or preventing them from wandering, De-light encourages the physical activeness in PLwD, which will be beneficial for both the physical and emotional wellbeing of PLwD in the long run.

5.1 Reflect on the NDB model

The NDB model has brought us a new perspective in understanding the wandering behaviours in PLwD. The model depicts the background and proximal factors that could contribute to the challenging behaviours, such as wandering, in PLwD. However, this model only lists what factors could contribute to challenging behaviours without indicating how one could make use of these factors in managing challenging behaviours in PLwD. Our research and design expand this model by applying these factors to explore a way to convert wandering behaviours into a guided activity for PLwD. De-light serves as a showcase for demonstrating a possible direction in applying these factors in managing challenging behaviours. The proximal factors have great potential for intervention, but they have not received enough conceptual development or usage in empirical studies (Algase, et al, 1996). Starting from this model, we made a step forward, to investigate the impact of modifying proximal factors for managing challenging behaviours in a real-life application.

5.2 Reflect on the co-design session

We realized that although PLwD have impaired cognitive capabilities, which means they have difficulty to describe their previous experiences, articulate their feelings and needs, and imagine future scenarios; it is still insightful to conduct co-design session with them together with their caregivers. PLwD can convey what they want and how they feel via their behaviours. The caregivers, who understand the PLwD better than the design researchers, can provide more accurate interpretations for the behaviours of PLwD. In addition, the caregivers are very likely to assist PLwD with using the design intervention, so caregivers should express what they like and do not like about the design concept from a user's perspective. The caregivers can also talk with designers about the previous experiences in caring for PLwD, and imagine future scenarios in caring for PLwD with the design intervention applied.

According to Rodgers, co-design involves the users in the whole design process for creating relevant and appropriate designs which can accomplish the main needs and desires of the users (Rodgers, 2018). The co-design session in this research is modified from the traditional co-design session to suit the capability levels of PLwD. This kind of modified co-design session has previously been applied in the development of The Magic Table (Tovertafel in Dutch), which has been put into practical use for improving the emotional wellbeing of PLwD (Anderiesen, 2017).

5.3 Limitations and future development

Our research and design are still in an early phase. The NDB model, Crisis Development model, video coding, co-design session and capability considerations do suggest our design is in the correct direction, but more details need to be taken into consideration. For example, PLwD are extremely sensitive to their environment, thus a moderate level of stimulation is essential for De-light to be effective yet it should not overstimulate PLwD (van der Plaats, 2009). In the near future, we should experiment with the loudness of the sound, the brightness of the light, the compliance of the glowing sphere, and the stiffness of the stick to find the suitable range for moderate stimulation. Since "the moderate level" is different for different PLwD, De-light should incorporate a few stimulation levels to meet varying needs of different PLwD.

Due to the limitation in budget and time, our current prototype is not robust and safe enough to be evaluated in the nursing home setting. After the prototype is developed to be robust and safe, the evaluation in the nursing home setting will be carried out as a series of co-design sessions with PLwD and their caregivers. Each co-design session will involve one PLwD and one caregiver. Based on these co-design sessions, we could identify what features in the design need to be improved. For example, is it likely for the PLwD to stumble on De-lights and thus, should we mount De-lights on the wall?

In the next step, we should put our design in the real-life context for field testing, and consider the possible interactions between our target PLwD with other PLwD who might be attracted by De-lights. We should explore the possibilities of involving more than one PLwD in the De-lights environment, and expanding our target PLwD to PLwD having other challenging behaviours. For example, De-light could be reduced in size and placed on the table to reduce vocalization in PLwD who are immobile yet constantly looking for stimuli (van der Plaats, 2009).

6. Conclusion

Our design, De-light, offers an alternative approach for caregivers to manage wandering behaviours in PLwD in nursing homes. De-light encourages physical activeness in PLwD by converting wandering behaviours into a guided activity with minimal input from caregivers, which could reduce the incidence of crisis events and beneficial for the physical and emotional wellbeing of PLwD. Our research and design approaches suggest the possibilities of applying NDB model, Crisis Development model, and the co-design approach in designing for PLwD with wandering behaviours. More research and evaluation are needed to develop our design further.

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