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INTenSE

Improving demeNtia care through Self-Experience

Definition of Self-Experience Practice in Dementia Care

social IT software & consulting
DCU Dublin City University
gruppo spes
MARTIN-LUTHER-UNIVERSITÄT HALLE-WITTENBERG
Maastricht University

INTenSE
- Introduction -

Self-Experience

Self-experience is scientifically proven to be the best way to create empathy and real understanding as a means to change practice, reduce issues and improve the quality of care. As a method to reach educational goals, self-experience is defined as “the process whereby knowledge is created through the transformation of experience” (Kolb, 1984). It is derived mainly from constructivist approaches such as Piaget’s who considered learning processes as an interaction between the individual and the environment, in which, during socialization, the individual constructs specific expectations or schemes about the world that are constantly either confirmed or refuted through experiences (Piaget, 1970). This theoretical foundation is the starting point for INTenSE and intents to create a modern self-experience tool. INTenSE aims to educate, equip and train health and social care professionals to better support and care for people living with dementia by developing innovative learning approaches based on the concept of self-experience.

Guidance for Recommendations Based on the Literature

This eBooklet delivers recommendations based on an intensive literature research and focus group discussions. However, the authors are neither qualified to formulate concrete details about the self-experience nor how its supposed to be created in particular. The entire INTenSE team have to decide how to use the recommendations to create the INTenSE self-experience intervention.

In order to use this eBooklet effectively it is necessary to understand the structure of this work. After the literature research, the editors concluded that it appears almost impossible to formulate general recommendations that represent all forms of simulations and can be adopted likewise. Therefore, the following eBooklet is subdivided separately into all interventions that were found through the intensive literature search. These recommendations should therefore only be adopted for the interventions to which the authors refer. Distinctively these interventions are grouped and stocked with a letter. Since there are several studies that include a particular intervention, numbers are added additionally to represent the study that is referred to. Meaning, the letter demonstrates the intervention group and the number demonstrates the concrete study that included this particular intervention (e.g. A = Virtual Reality Interventions; 1 = Adefila et al. [2016]).

Guidance for Recommendations Based on the Focus Groups

Additionally, findings from the focus groups are mentioned separately from other results since this represents the primary data collected by all partnering working groups that are involved in the project. Primary data should always be seen separately from all others and they should be classified and used accordingly. Everyone involved in editing the eBooklet agreed that there is still a need to formulate generally valid recommendations. These can be found in a separate form in chapter three. The applicability is given across almost all various interventions. Although these recommendations are supposed to represent the broad entirety of interventions, they must be examined critically. An assessment and verification of the feasibility should be carried out individually.

This eBooklet cannot be used by each and every individual. It is important to note that a foundational understanding of dementia needs to be present. Non-healthcare professionals may experience difficulties when reading the content. Furthermore, this comprehensive preparation of data is based on scientific literature and should be used in such a manner.

INTenSE
- Partners -

DCU Ollscoil Chathair Bhaile Átha Cliath Dublin City University

Maastricht University

MARTIN-LUTHER-UNIVERSITÄT HALLE-WITTENBERG

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Recommendations based on the literature concerning several self-experience interventions

Chapter 1

Overview of all Interventions

Virtual-Reality (VR) Interventions

Reference	Authors	Year of Publication	Intervention
A1	Adefila et al.	2016	myShoes project
A2	Hattink et al.	2015	Into D'mentia simulator
A3	Jütten et al.	2017	Into D'mentia simulator
A4	Jütten et al.	2018	Into D'mentia simulator
A5	Wijma et al.	2018	Through the D'mentia Lens (TDL)

Film Interventions

Reference	Authors	Year of Publication	Intervention
B1	Bailie et al.	2016	Ethnodrama □ *Barbara's Story*
B2	Prins et al.	2020	The Alzheimer Experience (AlzExp)

Game Interventions

Reference	Authors	Year of Publication	Intervention
C1	Maskeliunas et al.	2019	Serious Game iDO

Complex Interventions

Reference	Authors	Year of Publication	Intervention
D1	Gilmartin-Thomas et al.	2018	Alzheimer's Australia Vic Virtual Dementia Experience ™
D2	Gilmartin-Thomas et al.	2020	Alzheimer's Australia Vic Virtual Dementia Experience ™
D3	Leah et al.	2017	Simulation training for multidisciplinary teams
D4	Lorio et al.	2017	Multimodal experiential learning module
D5	Mastel-Smith et al.	2020	Dementia Care Bootcamp
D6	Mastel-Smith et al.	2019	Dementia Care Bootcamp

Non-Virtual Simulation Interventions

Reference	Authors	Year of Publication	Intervention
E1	Heward et al.	2019	DEALTS2
E2	Heward et al.	2020	DEALTS2

Theatre Intervention

Reference	Authors	Year of Publication	Intervention
F1	Dupius et al.	2016	Drama □ *I'm Still Here*

Role-Play Interventions

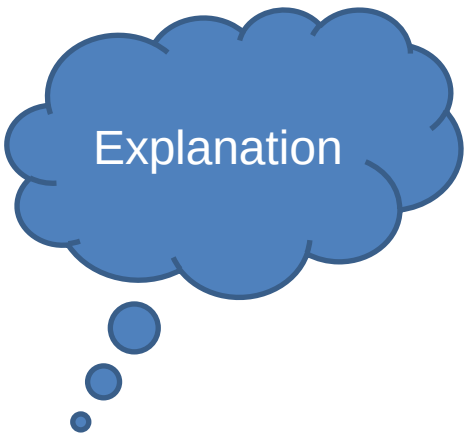
Reference	Authors	Year of Publication	Intervention
G1	Haugland et al.	2018	Scenario-Based Simulation
G2	Maharaj et al.	2017	Live-Model Simulation

Virtual Dementia Tour (VDT) Interventions

Reference	Authors	Year of Publication	Intervention
H1	Campell et al.	2021	Virtual Dementia Tour (VDT)®
H2	Jeong et al.	2019	Dementia LiveTM (DL)
H3	Han et al.	2020	Dementia LiveTM (DL)
H4	Han et al.	2020	Dementia LiveTM (DL)
H5	Han et al.	2020	Dementia LiveTM (DL)
H6	Kimzey et al.	2019	Virtual Dementia Experience (VDT)
H7	Kimzey et al.	2020	Dementia Live®
H8	Lorio et al.	2017	Virtual Dementia Tour (VDT)®
H9	Merizzi	2018	Virtual Dementia Tour (VDT)®
H10	Meyer et al.	2020	Virtual Dementia Tour (VDT)®
H11	Peng et al.	2020	Virtual Dementia Tour (VDT)®
H12	Sharkey et al.	2019	Virtual Dementia Tour (VDT)®
H13	Slater et al.	2017	Virtual Dementia Tour (VDT)®
H14	Slater et al.	2019	Virtual Dementia Tour (VDT)®

1.1 Virtual-Reality (VR) Interventions

Virtual reality interventions consist of a technical artifact that stimulates perceptions and senses of participants. The simulation itself can occur through several channels. Meaning, the usage of virtual reality glasses, screens, audio overlay systems, and others is predominant. The main goal is to simulate dementia through technical devices that influence human cognition and empathic skills.



Procedures of performing the intervention

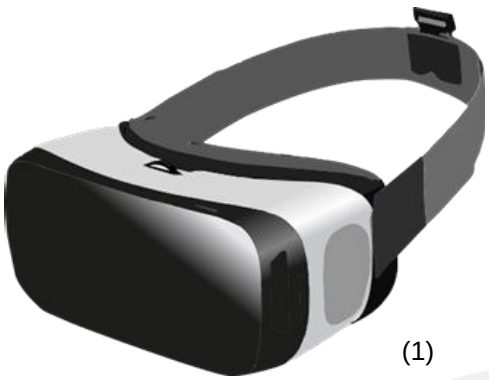
Before participating in a VR intervention, **participants** should be **prepared properly**. For using VR, participants need some time to adapt to the tool by walking through a neutral virtual environment without any disruptions [A1].

Experiences with *Into D'mentia (https://intodementia.nl/cabine/)* showed that caregivers **may react emotional** to the simulation. Therefore, the decision has been made that neither informal caregivers nor healthcare professionals are going to watch the movie alone. It seems to be advisable that trained researchers should accompany participants during the intervention in case of an intensive emotional reaction [A3].

Group discussions after exposure to VR seems to be an effective method for improving learning effects via self-experience. Through the discussion among each other, participants can reflect on their experiences and therefore, put it into perspective. Furthermore, participants can learn from each other's experience [A5, A6].

Short conversations with the **researchers** directly after the intervention may also have a positive effect on intensifying what the individual participant has learned [A4].

Furthermore, **using mixed method** interventions seems to be profitable. Meaning, the program consisted of qualitative and quantitative methods and were carried out within the same intervention. Most participants felt that an e-course, which followed a VR-intervention – added value to the intervention. The e-course, an online course that participants could follow at home, reflected on what had been experienced in the simulation movie in three 20-minute lessons [A4].



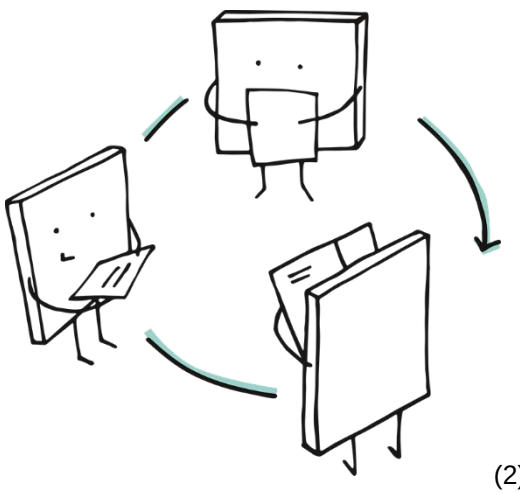
(1)

Barriers and facilitators

For the self-experience of dementia, the **progression of the disease,** typically categorized into mild, moderate and severe, should be considered and shown in the intervention. Thus, the simulation would be of interest for more care professionals working with people in different stages of dementia [A4].

A facilitator would be to **implement** the intervention **into standard care** and making it available for all healthcare professionals that could directly benefit from it [A6].

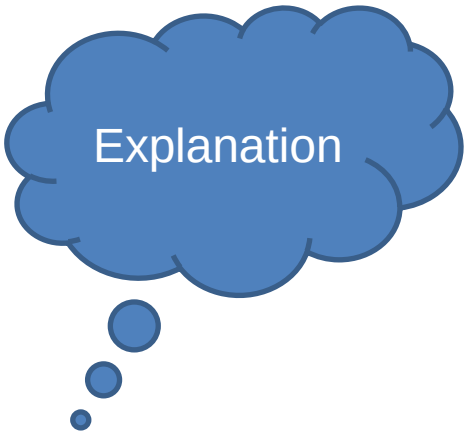
Generally, after participating in a VR-intervention, participants showed a better understanding and more empathy for the people with dementia they care for [A1, A2, A3, A6].



(2)

1.2 Film Intervention

The film interventions created a cinematic scenario that all participants got to experience. Several perspectives on the characters have been shown and the movies contained dementia specific information by demonstrating day-to-day challenges. Participants recapitulated their experience through an educational method that engages staff on an emotional level. The concept is to successfully prompt staff to be empathetic and shift towards a more person-centered care.



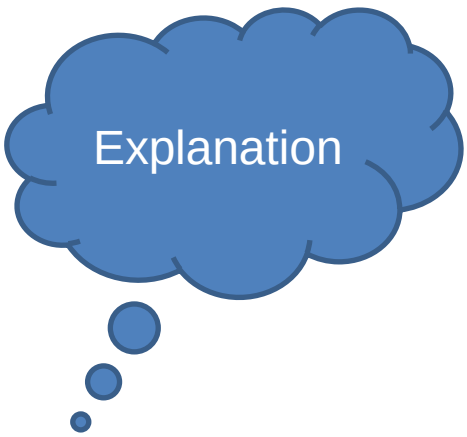
Barriers and facilitators

In study B2 more people watched the first scenes of the movie rather than the last scenes. It might therefore be relevant to **structure the scenes** of the movie starting with the most important topics and continuing with scenes of descending importance [B2].

(3)

1.3 Game Intervention

The game intervention aimed to create a computer game that is played to simulate dementia and relevant aspects that come with this condition. The concept is based on other already existing games, where every player has to take care of his own virtual entity. Social interactions and a simplified needs system challenged the players, however, provided a non-traditional environment to increase empathetic understanding of dementia.



Design

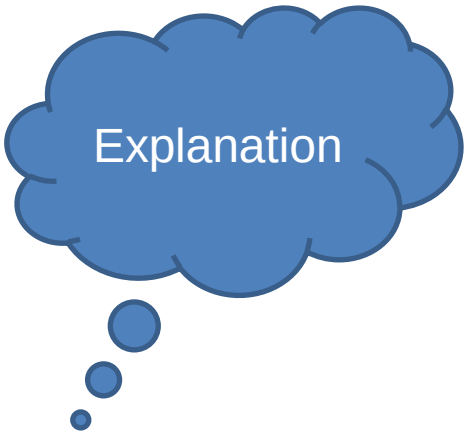
In order to develop a well-suited game for caregivers of people with dementia, one needs to make sure that the **in-game animations are properly designed**. Characters and surroundings should be less of a caricature style and more thorough-through. Creating a realistic environment complies better considering the topic of dementia care [C1].

Effects

Serious games appear to affect attitudes towards dementia positively; however, it remains unclear if one study is evidence enough to describe this effect [C1].

1.4 Complex Interventions

Complex interventions, contrary to other interventions, contained multimodal experiential learning components. Relevant elements can be observation, social-modeling, vicarious and direct learning experiences, and the classroom's purpose built environment. They primarily lasted for multiple sessions and included various interventions that appeared to be effective on their own. The idea is to provide participants with an encompassing experience to influence their habits positively. Complex interventions aim to promote participants' knowledge, attitudes, empathy, and self-confidence for people with dementia and dementia care.

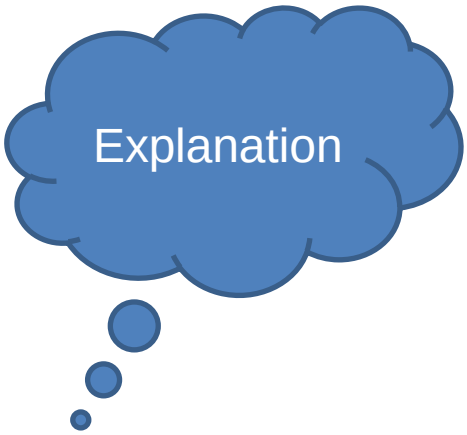


Procedures of developing interventions

Skill stations gave participants the opportunity to walk in patient's shoes, with activities mimicking the experiences of people with dementia, demonstrating feelings of confusion, isolation or frustration. Skill station are a useful tool for instructors to address specific skills in their classroom, for instance person-centered modules that teach competences with the flexibility to change as participants develop. Through this **external stimuli and active reflection**, participants engaged in a deeper level of understanding to promote compassion and empathy [D3].

1.5 Non-Virtual Simulation Interventions

The non-virtual simulation experience is a dementia education intervention, which places participants into the shoes of a person with dementia to facilitate a positive impact on practice. The materials used in the programs include PowerPoint slides, session plans, simulation instructions, handouts, and additional readings. These programs were designed to enhance consistency by providing a simulation toolkit covering person-centered care, communication interaction, behavior risk reduction, and prevention.



Standardization

In order to achieve a standardized dementia training across a large network it is recommendable to use a train the trainer approach. Meaning, everyone who is taking over an executive role in the program has to have the same background. Following a **given framework** ensures a similarity across the network [E1, E2].

Tailoring

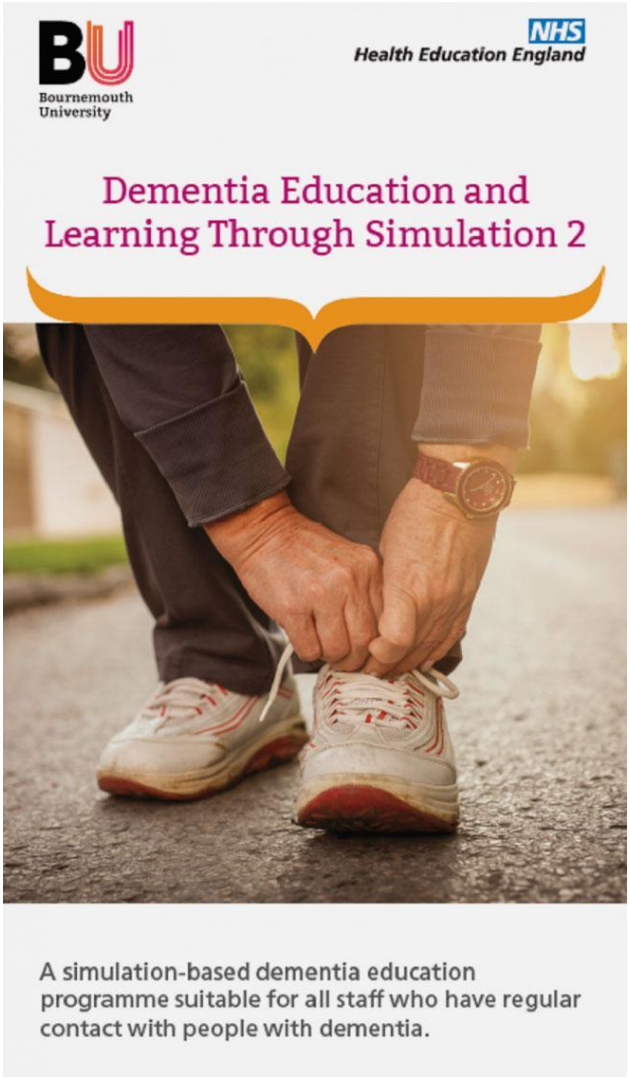
It appears to be an effective instrument if the non-virtual simulation intervention contains a certain level of freedom. Meaning, the **trainers** can **individually adjust** the training to their needs. Trainers were given the option to adapt the materials to suit identified training needs in their trust [E1, E2].

Time for discussion and reflection

Participants appreciated to have time during the intervention for discussion and reflection. Therefore, providing **space for verbal exchange** between participants and trainers can be a successful tool [E1, E2].

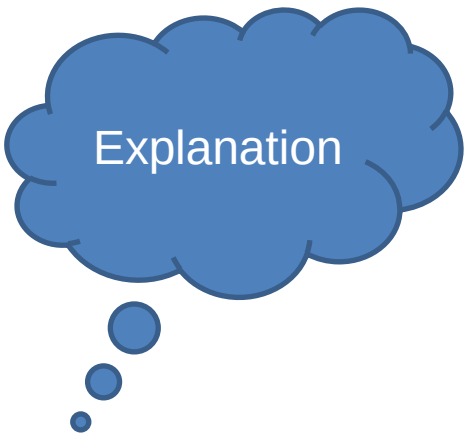
Simulation

Even though a non-virtual simulation has its limits, **creating a realistic environment** in which participants truly feel like people with dementia proved to be effective [E1, E2].



1.6 Theatre Interventions

Theatre interventions show a live performance, in which a certain external perspective can be taken by participants in order to not feel overwhelmed. Nonetheless, the audience is engaged on an emotional level and can therefore stimulate a reflection on their daily experiences. Several aspects of dementia can be acted out effectively during the play. The aim of this intervention is to increase the empathic understanding.



Development

For a proper development of a theatre play it appears to be most effective if an **interdisciplinary team** is working closely together. Since many aspects have to be taken into consideration, several experts and representatives of dementia need to have a say. The play involved research themes about the complexity of experience throughout numerous story lines of different people living with dementia from initial diagnosis to admission to a long-term care home [F1].

Intention

Participants remember scenes that addressed their emotions and feelings in particular. Therefore, new awareness and understanding reflects the notion that arts, including research-based dramas, **enable a shift in understanding** rather than recalling information [F1].

Emotions

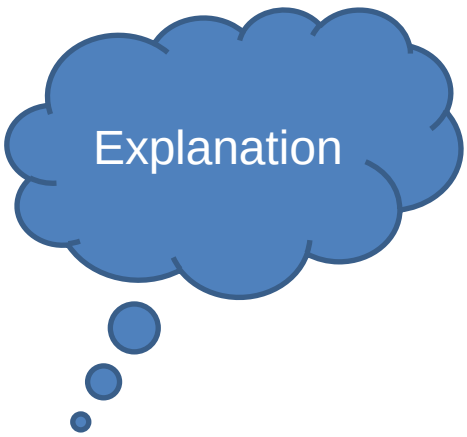
The **power of feelings and emotions** was linked with short- and long-term effects. Meaning, participants seemed to remember scenes that aroused certain feelings. For instance, themes were how living with dementia involves loss, challenges, and sadness. However, it also involves love, happiness, quality of life, and new possibilities [F1].

Knowledge

It is questionable if the play actually increased knowledge about dementia and attitudes towards dementia, but it can be concluded that **arts is a preferred way of communication** and therefore contains high potential [F1].

1.7 Role-Play Interventions

Participants are supposed to act out coherent patient scenarios in a given setting that nearly represents the environment in which one can encounter people living with dementia. Role-play interventions aim to use live-model simulation as a teaching tool in educational settings. Participants can improve their attitudes towards dementia as well as their knowledge of the disease.



Procedures of performing the intervention

Participants should be briefed for the used method of simulation and roles, equipment and learning outcomes of the scenario simulation [G1, G2].

The role-play appears to be most effective if all **surroundings** are **as realistic as possible**. Neither formal nor informal caregivers should be placed in an unfamiliar setting. This can simply be overwhelming and will lead to a negative outcome in every aspect. Typically this might occur in a university's skills laboratory similar to a medical unit [G1, G2].

Throughout the whole simulation, **participants should not be left alone** at any given point [G1].

Furthermore, students generally feel uncomfortable if confronted with such a task by themselves – considering the lack of experience [G1, G2].

A recommendation is to **form interdisciplinary teams**, as it would be in a real nursing home, in order to create an even more practical environment. Participants are forced to take over several roles and get to experience the intervention from every angle [G1, G2].

Provider

The success and the failure of a role-play intervention depends on the **skills and education of the facilitator**. The simulation can benefit greatly if the person in charge is highly dedicated. Neither a change in dementia attitudes nor an increase in knowledge about dementia can possibly be achieved if the facilitators are not certified [G1].

Time and amount of delivering the intervention

It is recommended to implement role-play more than once, because a change in difficulty can be gradual and supports the student's learning process. They have the opportunity to continuously apply their theoretical knowledge into a practical setting [G1, G2].

The intervention should **not last longer** than it would be in a real-life situation, because it creates false impressions [G1, G2].

Furthermore, **the period during the semester** when the intervention occurs is essential. Students tend to be less motivated at the end of the semester, especially if the role-play is neither graded nor mandatory [G2].

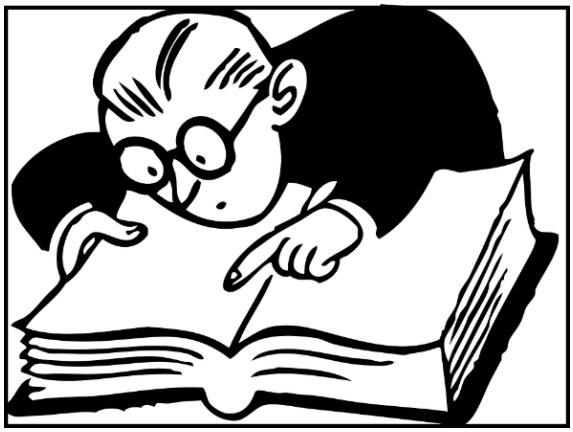
Strategies to maintain or improve fidelity

In order to properly develop and prepare a live-model simulation in form of a role-play, it is necessary to ensure **prior education** for every participant. Building a fundamental knowledge regarding dementia and its numerous variations is inevitable [G1, G2].

Barriers and facilitators

If possible, universities and colleges should **collaborate with local nursing homes or hospitals** and recruit residents that are willing to volunteer as patients in this scenario. The literature does not provide any limitations concerning the resident's stage of dementia, however, considering ethical aspects, such a decision needs to be carried out carefully for each individual. It appears to be problematic if peers have to act out the patient, because the understanding of the diseases may not be present. Tailoring the scenarios individually can be a relevant possibility to promote student's flexibility. Additionally, a properly developed role-play can support students to understand and use the concept of evidence-based practice [G2].

Role-play can **increase knowledge about dementia** significantly. Even though students received previous education, a noticeable increase result from the intervention itself. However, regarding **attitudes towards dementia**, role-play reported **no significant change** [G1, G2].



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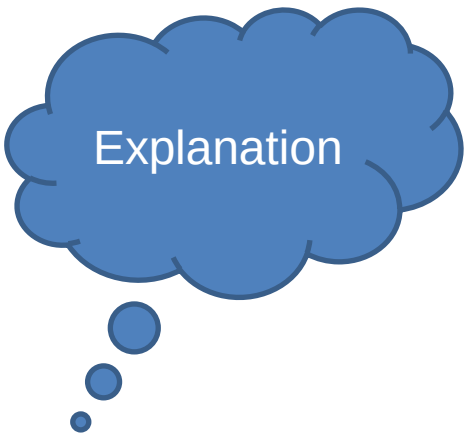
1.8 Virtual Dementia Tour (VDT) Interventions

The VDT is a dementia simulation that has been created to teach people the physical and mental challenges of those living with dementia. Building sensitivity and awareness in individuals that care for people with dementia is the main goal of the designed intervention. The virtual dementia tour (VDT) is not a computer-based tour and was originally developed in 2002 (Beville, 2002). However, even though the VDT has increasingly been introduced as the standard program for simulating dementia, it has numerous critical limitations.



General benefits and aspects to be assessed critically when performing a VDT

The VDT program facilitates individuals' understanding of the imagined experience of dementia and **promoted emotive, moral and cognitive aspects of empathy** [H2, H13, H14]. The VDT enhanced emotional and cognitive elements of formal and informal caregivers, which ultimately lead to a **reflection of their daily activities** [H13]. Additionally, healthcare professionals and informal caregivers changed care strategies through the dementia simulation experience and therefore
improved communication as well as their attitudes towards people with dementia [H3, H4].

VDT revealed no significant change in knowledge about dementia but **increased confidence towards working with dementia patients** [H8, H9, H10, H11, H12, H13, H14].

The VDT alone may not be enough to support a change in knowledge. **Additional teaching and learning** strategies are necessary [H1].

Due to a low-evidenced fidelity, the VDT assumes that people living with dementia always suffer from physical and cognitive problems, however, the program places all those problems onto one person. Differentiating between common problems and all problems that could possibly occur seems essential. It may lower the risk of **participants feeling overwhelmed** [H9].

VDT represents an abusive reality, where trainers are not allowed to intervene even when students ask for help [H9]. The way this experience has been created does not support the way people interact and needs further adjustment [H9]. **A competent offer of support should be available for all participants at all times**.

Considering the Code of Human Research Ethics published by the British Psychological Society (2010), it is highly **questionable if the VDT program remains ethical**. A revision of several aspects, such as wearing extra-large gloves filled with unbursted grains, can vanish ethical concerns [H9].

The VDT is designed following a very generic view on dementia and **does not** take into **consideration all the types of the disease**. Further development should considers several aspects of the disease including positive emotions such as love, enjoyment, and attachment [H9].

(5)

Time and dose

The simulated virtual reality dementia experience could be beneficial to students at **any point** in their undergraduate curriculum [H1].

Modifications

Modifying and replacing elements of the VDT program can reduce participants' stress, as it diminishes the rather difficult parts [H11]. For instance, participants were supposed to wear acupoint slippers for simulating foot pain instead of having dried corn kernels in their shoes [H11].

Recommendations based on the focus groups

Chapter 2

2.1 Recommendations from Focus Groups with Professionals

Development of Self-Experience Interventions

A) Virtual Reality interventions

Impact

Augmented Reality can be used to impart experiences such as hallucinations and misjudgement of reality by incorporating virtual effects and acoustic stimuli. Experiences in virtual settings can be used to prepare teaching sessions by providing impulses on the topic. Non-technical self-experience practices such as role playing or a dementia parkour can be included in VR apps. (DE)

VR can be used to trigger curiosity. (NL)

VR could be incorporated to simulate dementia as participants could be exposed to the sensory and perceptual issues people with dementia may experience. (IE)

"I would haved loved something like a headset…and look at it from somebody with dementia point of view around the environment." (Professional, IE)

Technical conditions

There are several important technical aspects or conditions when considering a self-experience intervention like VR: for instance, for VR you need a 'heavy-duty' computer and 'know how' on how to connect etc. Using VR also means having technical know-how and choosing the type of equipment (e.g. VR with mobile phone). VR-applications for mobile phone (with the cardboard glasses) are associated with lower quality but works quite well and you can easily reach a lot of people. Perhaps, it would be beneficial to include e-learning. Furthermore, it is important that technical support is available, when necessary. (NL)

Ethical issues

When developing and applying a VR intervention, ethical aspects must be considered, such as competent supervision of the self-experience. Ethical reflections are indispensable, e.g. how intensively can a person, who does not suffer from dementia, be confronted with dementia-specific experiences. (DE)

B) Movies

Impact

Film scenes could be the starting point of an intervention and should be combined with the imparting of knowledge. Using films with solution strategies appears to be difficult as this implies that there is a simple solution to the challenges of coping with people with dementia. There is a risk that the film communicates a single strategy for all symptoms, while it would be appropriate to specify that the film must be accompanied by adequate training where it is explained that the intervention should be personalized and tailored on the individual. The film is useful for giving just some general examples. (DE)

Movies present the possibility of seeing a situation from different perspectives and the viewer can therefore get an impression of how people view the same situation in different ways. (NL)

C) Gaming

Impact

Video games could sensitize users for their own actions when coping with people with dementia by evoking positive or negative reactions to one's own activities from one's counterparts. Depending on one's own actions, one may or may not get further in the game (gamification). In this way, situations for coping with dementia could be tried out. (DE)

E) Non-virtual simulation exercises

Impact

How it feels to reach your own limits and the related anger and fury can be experienced with the help of a dementia parkour. A dementia parkour is a course with different obstacles related to experiences of people with dementia, e.g. incorrectly assignment of terms to things. (DE)

(6)

F) Theatre

Impact

Aspects from the theatre (e.g. improvisation) can support the situational competence, i.e. ability to adjust quickly to new situations. This also includes accepting the person with dementia's reality even when opposed to one's own perception. This simply means oneself may experience a situation differently than somebody else or their impressions differ. Knowledge does not mean understanding.

Empathy can be enhanced with creative impulses from which a deeper understanding can develop. Understanding can lead to new forms of action and a new motivation to act. The prerequisites for this must be established by professionals. Theatre techniques with changing roles or self-experience exercises with playful handling are also recommended. Playful improvisation is nearly always successful if it is guided. (DE)

"The better I can empathise, the more I understand this illness, the more I understand the affected person's behaviour." (Professional, DE)

G) Role Play

Impact

The idea of role playing can be beneficial to assess and evaluate specific situations where caregiver and health care professionals can fail or succeed in person-centered care. (IE)

Organization of role-play interventions

When using role-play as a method for self-experience, it would be good to make use of good actors, who are not known to the participant (as this makes it difficult to predict the reactions during a role play). Role-plays can be video recorded and discussed later on. Although recording ones (re)actions can be confronting, such an approach elicits reflection and discussion. Privacy issues have to be safeguarded. By making use of a role play with actors, one can play the professional, and directly recreate a case. (NL)

Other interventions

Impact

360-degree videos can be developed using different perspectives, such as the health care professional or also the person with dementia. It is also possible to include the options to change perspectives during a case. During such 360-degree experience different scenarios/options can be presented to the participant. (NL)

Video home training is not per se a self-experience intervention, but a learning approach by watching a situation back. It could show the caregiver how the partner (person with dementia) responds to behavior, and add psycho-education to explain influence of different responses. Video-interaction-guidance was mentioned as something already implemented in practice. Watching yourself and your response is a powerful learning experience. (NL)

Although not by definition a ‘self-experience’ method, e-learning could also be an example to involve case managers in a discussion about their learning experiences. For instance, the Powercourse dementia shows movies made from the perspective of the person with dementia (e.g. https://www.marthaflora.nl/over-martha-flora/power-course-dementia/). (NL)

Challenges in dealing with people with dementia and how to professionally cope with them could be conveyed through an app designed to integrate everyday life. Researching various everyday experiences can promote self-experience. Best practice examples for problematic situations in dealing with people with dementia could be accessed easily via such an app. (DE)

Technical conditions

3D videos as a method can be used via mobile phone. (NL)

Symptoms of dementia

The accounts of health care professionals have implications for how symptoms of dementia may be stimulated to increase understanding and improve dementia care through self-experience practice. It seems that the psychiatric symptoms of dementia are the most difficult for health care professionals and the general public at large to fully comprehend. Thus, it may be important to place more of an emphasis on these when developing a simulation toolkit. Examples of such symptoms include hallucinations, sleep-wake behavior, delusions, and paranoia, and these are more closely related to dementia subtypes including Lewy body dementia, frontotemporal dementia and vascular dementia. (IE)

Memory issues are certainly important to consider for this intervention, they must also be presented in parallel with the other non-cognitive symptoms that people struggle so much to come to terms with. (IE)

A simulation of dementia may generalize the disorder to one that is homogeneous across the dementia population. Thus, it was suggested by the participants of the focus group that a disclaimer is needed to explain that not everyone with dementia will experience the simulated symptoms, and that these are just some of the symptoms people with dementia may have. (IE)

Participants thought that distorted perceptual/sensory simulations portray a negative perception of dementia and that caution must be taken. Perhaps a negation could be included to indicate that everyone with dementia will experience the simulated symptoms. Some participants proposed that playing to the strengths of people with dementia may be a possible strategy to overcome this caveat. Hence, with every dementia-related issue simulated in the intervention, an example of a solution-focused tactic to improve the issue could be displayed in parallel. (IE)

Competences

Important competences which should be taught are: empathy (DE, IE, IT, NL), listening skills (to be able to listen at people with dementia openly) and open-mindedness (to avoid prejudices and to accept people with dementia). (IT)

Communication is another important competence for professionals that could be integrated into the intervention, for example by means of creating examples and discussing these with participants later on. (NL)

Furthermore, attitudes towards people with dementia may be important, but may be difficult to teach, as this may be a personal characteristic. (NL)

"But I think there is always an ethical issue involved" (Professional, DE)

According to the professionals, it is fundamental to communicate respectfully and with the right distance. Maintaining the right distance means keeping respectful limits so as not to become personally involved and reactive. (IT)

The attitude to be conveyed in relation to people with dementia should furthermore be one of seeking, not knowing. It should be about collectively finding out what has helped in relevant situations. However, one must also learn to cope with an approach that does not work out, since there are no general solutions for difficult situations. (DE)

Professionals also need to differentiate between one's own needs from those of others (here: people with dementia). This type of cognitive process is a psychologic work of awareness on oneself. It would therefore be necessary to integrate this type of psychological work in the training of health professionals. (IT)

Knowledge should be imparted about the situation-related competence of people with dementia. An intervention should train the capacity of being able to put one's own reality in the background in order to perceive and recognize the reality of a person with dementia. (DE) Providing insight in dealing with dementia for the caretaker via for instance virtual reality can heighten understanding and help someone to react differently to certain situations. (NL)

The theme of understanding is central to the development of a simulation toolkit aimed at capturing the experience of dementia. A critical point to consider is that the environment in which an individual is placed has a bearing in how they behave or how they might experience dementia. Thus, when creating a simulation of dementia, it might prove worthy to explore how people with dementia interact with their environment, and how certain environmental factors can improve or worsen their symptoms. (IE)

Taking your time and being patient when dealing with people with dementia should be taught in self-experience training sessions.

Non-verbal communication

Unconditional regard for the person with dementia is more important than being able to comprehend the dementia experience, especially in the advanced phases of dementia where understanding is only possible to a limited extent. (DE)

The important role of non-verbal communication when in contact with people with dementia must be observed and should be taken into consideration when developing self-experience scenarios. (DE, IT)

Receiving the diagnosis dementia

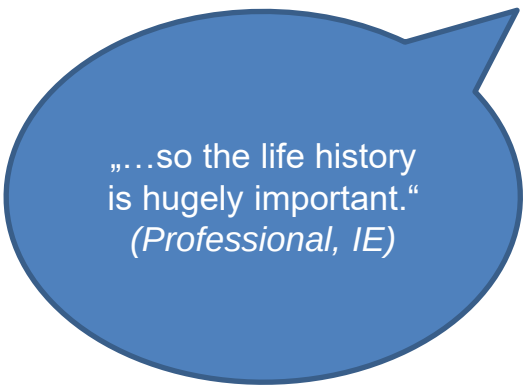
It could be valuable to simulate the experience of a person with dementia receiving a diagnosis, to get across the message to health care professionals of how difficult it really is for people seeking help for a diagnosis. This might resonate with health care professionals and GPs, who are mostly responsible for providing this support, and could have potential for generating reflection in how they previously dealt with dementia diagnoses. It is hopeful this might translate into more efficacious diagnostic support for people with dementia and their caregivers, especially in primary care services. (IE)

Theoretical models or frameworks for self-experience interventions

Professionals believe that there is a lack of adequate training regarding the theoretical, psychological and practical aspects of dementia assistance for health care professionals. For them it seems to be important to stress theory (e.g. the neurological and behavioural aspects of dementia) in a self-experience intervention. (IT)

Furthermore, professionals highlight the need of a unique model of care assistance for all types of dementia. It is important to find a relationship mode that works for all dementias, not just Alzheimer's. The Montessori method would be suitable for all types of dementia. Identity, relationship and person centred care are the cornerstones of the approach. This would allow for a single, more flexible and agile instruction manual to manage patients with dementia. (IT)

Focusing on biographical work in the care of people with dementia can narrow the perspective. Accordingly, this aspect should be taught/reflected upon within the self-experience tools. (DE)



Person-centered care is important when dealing with people with dementia and should therefore be part of a self-experience intervention. (NL)

Education and training themes

Education and training themes are key to the development of a simulation toolkit. (IE)

However, it is crucial to keep in mind that dementia itself is poorly understood and that education is still needed to explain and teach people how dementia works, as well as how the different types of dementia can present in healthcare settings. (IE)

Self-care skills

Nursing staff must not only acquire competency for coping with people with dementia but also self-care skills so that they can do justice to themselves and to their demands on nursing or care within the framework of institutional guidelines. Health care professionals must preserve professional detachment so that work procedures can be maintained. (DE)

Health care professionals often have to deal with the feeling of failure derived from the management of these patients who are very difficult to assist due to their cognitive and behavioural problems. Therefore, if a health care professionals is very stressed or easily irritable, he or she presents with a high risk to respond negatively/incorrectly to the patient and therefore compromising the relationship. Part of the intervention should be to help and train operators by providing them with psychological tools that can help them become aware of themselves (their limits and weakness) and create constructive relationships with both colleagues and patients. (IT)

„Working on oneself might be the starting point to reach the other.“
(Professional, IT)

Organization of a Self-Experience Interventions

Modules

Combining approaches/methods and to promote interaction adds value to self-experience tools. To enhance self-experience, it could be valuable to connect literature and theory to practice. For example, first read literature, then apply self-experience glasses, and discuss/share thoughts with a professional (such as a case manager). Another option is to organize a group meeting to discuss thoughts and experiences, and provide the opportunity to be more profound. (NL)

The more specific the focus is of a training course, the fewer clients you will find. Accordingly, training should be designed in a more general manner, possibly with a selection of modules which include several scenarios/situations. A new intervention should be interesting for a big group of people, though fitting with the personal situation of the participant. It is important that such scenarios do fit the situation of the professional. (DE, NL)

In a modular intervention, one's own experiences with people with dementia could be addressed. The next step would be to make suggestions for successful communication/interaction. It must be remembered that reactions and behaviours are individual. (DE)

Simulation tools could be seamlessly integrated in a lot of different training programs that already exist in healthcare settings. Such a tool would add a holistic element, whereby participants can learn about the actual lived experience of dementia alongside other training, therefore consolidating the experience of simulation tools as well as other training programs. (IE)

Didactics

With the use of some small didactic exercises, the acceptance of various perceptions can be trained. The didactic conception of educational interventions is of great importance. (DE)

Target groups

Training sessions must be adjusted according to the target group, particularly regarding complexity and time required. Generally, however, an appreciative approach and an appropriate attitude towards people with dementia should be imparted. (DE)

Self-experience practices should be didactically processed in a way that is appropriate for the target group. Not everyone is suited to be a trainer. (DE)

It has been suggested a possibility of an integrated intervention considering all the actors that are in contact with the person suffering from dementia. It would be desirable to work with the whole group of people that enter in contact with the patients: the health staff, the caregiver and the family members. (IT)

„You have to help people understand what they are experiencing.“ *(Professional, NL)*

Participants also felt that it was important to consider the stage at which people are at before undergoing a simulation intervention. Such an experience could trigger unwanted feelings of distress, particularly for those at the beginning of their dementia journey. In this regard, it seems as though a debriefing process would be essential to include in case participants felt in any way distressed following the experience. (IE)

Contextual factors

It is important that the professionals who are going to offer the intervention, have experienced it fully themselves, so they see the added value for their 'customers' instead of just the additional work that it will give them. Related to this it is important for professionals to experience the added value of the intervention. Furthermore, it is important to provide a standard training when purchasing the product. Once implemented, it could be beneficial to have regular follow-up contact to collect the users' ongoing feedback, and offer the possibility to follow a refreshment course. (NL)

The training must be accompanied by a practical experience (field training). (IT)

Curiosity, calmness and humour all play a part in self-experience practices. (DE)

It is of huge significance to acknowledge the barriers that health care professionals face in the implementation of dementia training in their respective roles and settings. It is important to note that leaders or so-called 'dementia champions' are absolutely necessary to maintain new training tools in healthcare settings. (IE)

New interventions should be innovative, enjoyable and impart knowledge at the same time. (DE)

Co-creation and involvement of different stakeholders as well as already thinking about implementation are important aspects when developing an intervention. (NL)

When developing technology-based self-experience tools with regard to dementia, it would be helpful to have interdisciplinary cooperation with departments already using or developing such technologies. (DE)

Implementation of Self-Experience Interventions

Framework conditions

When interventions that promote empathy are used, attention must be paid to possible burn-out reactions or traumatization of the users if they are working under inadequate conditions. This means that an intervention must also take the framework conditions and context of dementia care into consideration. Self-experience must include training on how to transfer what has been experienced into practice. (DE)

Furthermore, a concept for implementation must be developed in conjunction with the organisation. Opportunities for implementation must be created by the management level so that the training remains sustainable. Simulation exercises have to be checked to find out how often they should be applied in order for sensitization to be sustainable. (DE)

Technology-based self-experience practices should be linked with face-to-face counselling or with a person who can be contacted if necessary. During self-experience training, the participants should be given not only the opportunity to retreat somewhere but also that of interacting. (DE)

The group composition of the participants plays a role. Groups free of hierarchy should be aimed for. If managers are in a group with employees, this may inhibit their participation due to prejudice or fear. (DE)

Various strategies should be offered/imparted so that each interested person can find something that suits herself/himself. There is not just one way. For the health care professionals it would be helpful to have an overview of the various suggestions on how to do things differently and find one's own way. (DE)

Barriers and facilitators for implementation

Time: Health care professionals are often busy with dealing with crises, and it may not be the ideal time for new technologies. Therefore, it could be valuable to implement this self-experience practice early on. Furthermore, offering such interventions should be 'low-level' to avoid putting in too much time. (NL)

Attitude: Another aspect that could be a potential barrier is that the professional must be open to try out new technologies, and that there is a higher threshold to use because of no affinity or experience with technology (DE, NL)

Costs: As there will always be costs related with the implementation and use of interventions, one important aspect is the financial imbedding: who will for example reimburse such interventions? (NL)

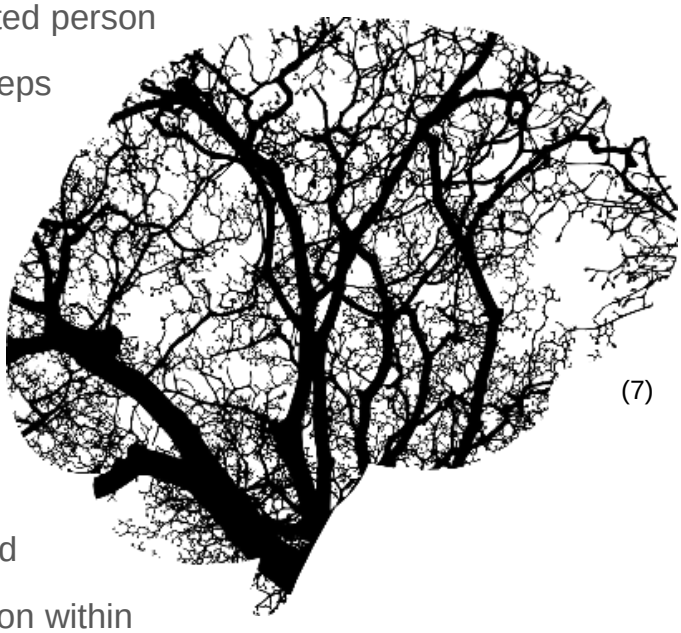
Commercial aspects also impede the dissemination of self-experience tools. (DE)

Lack of awareness: partly related to the previous barrier on attitude is the lack of awareness. The care providers must know about the existence of the new tool in the first place, and next also know exactly how and what is possible in the actual use. (IT, NL)

Therefore, the terminologies used should be taken into account since potential users may require explanations for terms such as "self-experience practice" or "technology-based". (DE)

Lack of availability: Technology is not really used in the augmented reality techniques built for managing dementia. The scenarios that are constructed to make the patient believe that they are in another place (e.g. the train or bus stop) are not tools characterized by the use of technology. There is a lack of use of technology in these contexts, IT should be more advertised between health care professionals. (IT)

Dedicated person: Have a dedicated person for 'innovative technology' who keeps it on the agenda of the team and looks for (new) applications of the tool. If possible, have a second dedicated person, as back-up when the first one would be unavailable. Such dedicated person should be a fixed person of contact for this application within organization, so it is immediately clear where users can direct their questions. (NL)



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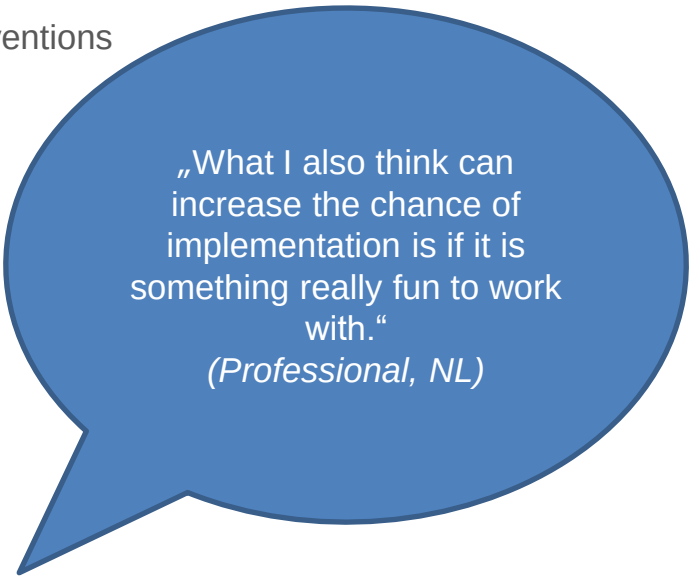
Accessibility: Another facilitator relates to the accessibility of the intervention. One suggestion was to develop a database and share such interventions via a sort of library, if possible, at low costs ('to try out'). A second suggestion was to to offer the intervention via an online platform, increasing the use on a larger scale (implementing on multiple locations).
Finally, the intervention could be made available in an *app-store*. However, the latter can result in less control in terms of monitoring. (NL)



Positive promotion: It is important that the developed intervention appealing to work with, as this will increase the potential for implementation. (NL)

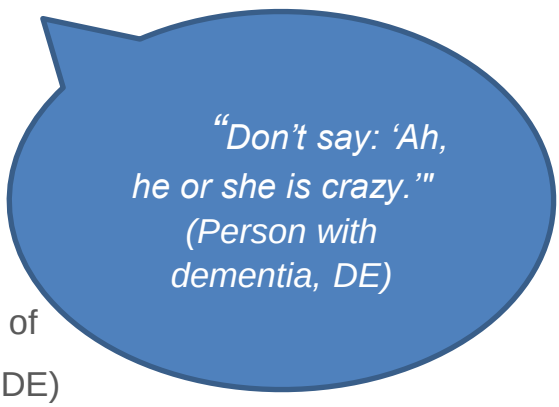
Furthermore, the technology should facilitate instead of showing all the possibilities. (NL)

2.2 Recommendations from Focus Groups with People with Dementia

Symptoms of Dementia

A simulation intervention should consider that people with dementia expressed concerns in the realisation that their symptoms will worsen over time and fear that someone will be there to help them when they need it. (IE, DE)

It is very important for people with dementia how other people respond to them. Thus, the change in behaviour of others towards the people with dementia can be deemed a symptom or side-effect of dementia. Friends and family tend to overstep the boundary of their relationship and assume the role of carer. Those around the person with dementia were mentioned as often taking over tasks the person was capable of doing themselves. It is frustrating for the person with dementia if friends and family taking over certain tasks without being asked, finishing the person's conversations, and offering help when it is not required. This ultimately impacts the individual's ability to live independently, and in how they view themselves; for example, as incapable of dealing with their own challenges. (IE, DE)



Understanding of Dementia

Simulations should consider that people have a life besides their dementia, and more specifically in the context of dementia care for lesbian, gay, bisexual, transgender, queer and intersex and other individuals. (IE)

A limited understanding for people with dementia might stem from a lack of awareness that people can still live well with dementia and that not everything is lost with a diagnosis. (IE)

Other people's understandings can influence the experience of dementia, and perhaps this can be communicated through simulation tools. An emphasis could be placed on how the environment can shape an individual's symptoms and how other people's behaviour may come to interfere with the individual's life. As a result, a simulation tool aimed at increasing this understanding might better inform friends, carers and family members how they should approach their loved one with dementia. (IE)

It should be considered that receiving a diagnosis could be frustrating for the person with dementia. (DE)

It is important for people with dementia to have like-minded people and the opportunity to share experiences. (DE)

For people with dementia it is important to be accepted the way they are or the way they once used to be. Mistakes should not be highlighted. (DE)

It should be noted that some situations can simply not be explained. The questions is if they always need to be comprehended. (DE)

Movies should show a variety of dementia experiences. They can be used as a starting point for discussions. The trajectory of dementia should be taken into account, and not only single moments points of the disease. (DE)

Development of Self-Experience Interventions

Heterogeneity of dementia

It is majorly important to understand the diverse range of symptoms that can be present in people with dementia. It is crucial to capture informal carers' experience on this matter. Indeed, some of the more typical memory/cognitive deficits were reported by informal carers but it is essential to consider these symptoms from the point of view of someone with dementia. (IE)

It seems essential to include psychiatric symptoms, like hallucinations, or sense of anxiety/worry, in a simulation toolkit of dementia as they appear to influence the lives of informal carers and their loved ones with dementia. (IE)

Concrete experiences of relatives of people with dementia could be a suitable tool for training or teaching. (DE)

The type of dementia should be considered, e.g., Alzheimer's dementia or vascular dementia. For example, there are differences in communicating with someone with Alzheimer's dementia or vascular dementia. (NL)

Due to the individuality of those affected and the heterogeneity of the symptoms, the disease becomes more difficult for outsiders to understand. In stressful situations, the understanding of the symptoms of the disease declines enormously which should be considered in simulations. (DE)

It would be important for simulation technology and self-experience practices to be holistic and inclusive in order to reach as many people as possible and remain accessible to anyone interested in taking part. (DE, IE)

It may be crucial to highlight the heterogeneity of dementia so participants are granted an opportunity to form a well-rounded awareness of the different types of dementias, the various symptoms that exist within each diagnosis of dementia, and the positive as well as the negative aspects of living with this disorder. (DE, IE)

Understanding of dementia

It may be of utmost importance to get the message to people across, that dementia is more than a memory disorder and non-cognitive symptoms can often have a more significant bearing on the lives of people with dementia and their carers. The simulation toolkit could therefore be more specifically aimed at increasing understanding around these non-memory-related symptoms as they seem to be the most poorly understood. (IE)

„All of that kind of stuff, it‘s that, how they respond to you.“ *(Person with dementia, IE)*

There is also the effect of the medication, which should be made perceptible as well. What does it mean to live permanently with psychotropic drugs? (DE)

A progressive loss of abilities should be emphasized in the training. Simulations should consider situations in advanced dementia, where one can only guess what the person with dementia need. (DE)

Questions towards understanding of dementia: (DE)

- ✔How can a situation where objects can no longer be recognised or used be made perceptible?
- ✔How it feels to be called "ill" in various situations should be made tangible.
- ✔How do the dementia symptoms cause anxiety?
- ✔How could this anxiety be made perceptible?
- ✔What does it feel like if I want to do something but another person does not allow me to because they do not have confidence in me?

„I think people should stop thinking about Alzheimer‘s. Think about what they would like in their life.“
(Person with dementia, IE)

2.3 Recommendations from Focus Groups with Caregivers

Understanding of dementia

It is important to consider the diagnostic phase that informal carers and people with dementia often struggle with. In terms of a simulation toolkit aimed at improving understanding of dementia, it may prove useful to incorporate a prodromal section where participants are given an opportunity to appreciate how dementia might appear in the early stages and how its symptoms can be identified. (IE)

It could be useful for professionals to view the diagnostic process from the lens of someone with dementia, to gain insight into how lacking the process can be, and how this process has implications for the people with dementia and their informal carers. (IE)

„When she lost the words, our gaze remained,…the idea of also trying this nonverbal communication channel is the right one.“
(Informal carer, IT)

The simulation could include aspects of the continuing uncertainty (regarding the dementia) and the unpredictability of dementia and its symptoms. (DE)

Carer’s support

It should be taken into consideration that emotional aspects are very difficult for family members to manage because they can cause difficulties both in the relationship with the person with dementia and personal psychological problems with themselves; while it is easier for healthcare workers to provide assistance because there is an emotional detachment. (IT)

Structure and content of self-experience interventions

Self-experience interventions should include several strategies: put oneself in the shoes of others, understanding and acceptance. (IT)

- ✔ Only by trying to put oneself in the other's shoes, one can perceive the level of sensations and the psychophysical state of the person with dementia.
- ✔ Another important step for self-experience is try to accept the disease by getting as close as possible to what may be the emotional, mental and even physical state of what the person with dementia feels.
- ✔ Acceptance comes before understanding, because if you are not ready to accept the illness, you will not even be able to understand it. It is a very powerful self-experience strategy to experience dementia as a natural fact, as something that is part of aging naturally, to be less frightened and to be able to deeply understand the persons with dementia. One can understand people with dementia from their emotions, e.g., you can understand that when people start to lose their memories they become very sad.

VR-glasses could be a suitable method to self-experience dementia, but besides an advantage, it could have a disadvantage being that VR on the longer term may be regarded as 'artificial'. (NL)

The value of combining methods was mentioned. Combining theater play (for example) and a post-discussion could be more effective and profound than purely putting on VR-glasses. (NL)

Pantomime might be advantageous, steering the spectators' attention to the non-verbal form. Various situations could be presented to build up experience with interactions that are sometimes successful, sometimes unsuccessful. (DE)

The contents shown in simulations or the media should not give a one-sided picture of the disease and its effects. If possible, illustrations should be real and not fictitious. (DE)

„To talk about it and see such a play is, in my opinion, much more profound and effective than putting on glasses and then experiencing it.“
(Informal carer, NL)

emotionally

presented

one-sided

Technical aids for simulation must function in a target group-oriented way. (DE)

Films can promote understanding for the disease and and be moving if dementia is realistically and not in a manner. (DE)

An idea for the simulation: The person should absorb information, which is made difficult by various distractions. (DE)

Facilitators and barriers

It is important to accept, that it is not always possible to completely understand what the person with dementia wants to say (in case of e.g., aphasia). The choice of words and the body talk is very important. This should be taken into account when developing a simulation intervention. (NL)

The young generation with their competencies to use technical options should be involved in the development of self-experience interventions. (DE)

Ethical and relational aspects

Showing trust and dignity are important aspects when caring for someone with dementia. (NL)

The informal carer knows the person with dementia on a different level than a professional. The person he/she was before dementia progressed is therefore not always known to the professional, and the informal carer may therefore have a better understanding of what is possible (and what not). Especially when the informal carer is the spouse or a family member. (NL)

Knowing someone often means knowing one's history and possible life events, which might relate to behavior of the person with dementia. For example, someone who experienced World War II might have a trauma, which may not be known to a professional. (NL)

Showing compassion from a professional perspective can be an important competence, besides empathy. However, it was questioned in how far this could be learned. (NL)

A personal connection between the professional and the person with dementia and the informal carer is important. (NL)

Implementation of Self-Experience Interventions

It is crucial to consider the possible caveats of these interventions and plan how we might overcome these caveats to prevent psychological distress in those taking part. Managing the reactions of participants to the intervention would be critical to incorporate into this process. Perhaps, an extensive debriefing process would be useful to circumvent the potentially traumatic nature of the simulation. (IE)

The limits of what is reasonable for the participants must be respected. (DE)

Slow and appropriate introduction to technical applications is essential. (DE)

When explaining dementia, it is essential to take into account what prior knowledge is available and what can be absorbed by those involved in the current situation. (DE)

The staff needs social competence and more knowledge about coping with people with dementia. The time required for applying these competences has to be taken into consideration. (DE)

Professional carers need more background knowledge about dementia. (DE)

The context and life story of the users (experience with technology) have to be taken into consideration. (DE)

General recommendations transferable to various self-experience practices

Chapter 3

The recommendations on various self-experience interventions should be taken with caution due to their evidence background. Some recommendations have been derived from very specific programs described in some studies, which have limited transferability.

Basic considerations

"Emphatic Understanding" of the disease has the most potential to **impact behavior and communicative** practice of professionals and informal caregivers [H14].

Based on the findings of the present study, a dementia simulation program like the Dementia Live ™ program may give caregivers maximized benefits if the program is **included as part** of the education of caregivers of people with dementia [H3].

A **lecture program accompanied** by a **simulation program** led to a higher level of well-being in terms of happiness and lower level of helplessness than the lecture program alone [H5].

Simulation does not improve knowledge beyond what students have previously learned in lectures [H7].

Students should be **placed in an environment that mimics** the common challenges that patients with dementia face on a daily basis [H8, H11].

No simulation will ever **fully allow students to understand** the lived experience of dementia, but it might help to improve understanding [H10].

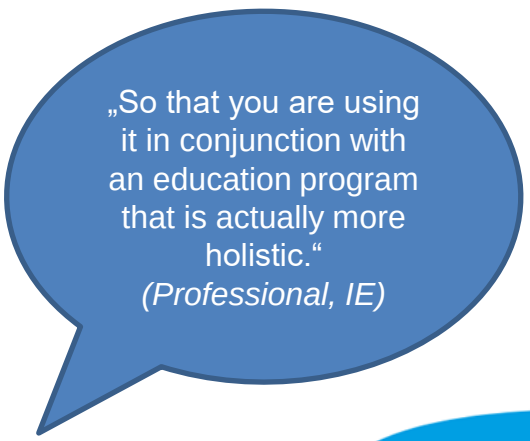
Caregivers who participated in a simulation program led to a more frequent **use of emotion** focused coping strategies than caregivers who did not participate [H5].

Procedures of developing interventions

Virtual experience may **complement rather than replace** knowledge-based university education [D1]. The Virtual Dementia Tour in combination with traditional lecture-based teaching methods ensures foundational knowledge about dementia [H10].

Course material should be **reviewed regularly** in order **to remain relevant** considering the future needs of students, while working in collaboration with practicing medical practitioners and pharmacists, is highlighted [D2].

Participants progress using different teaching techniques- didactic, case discussion, skill stations and full immersion simulation, moving them through the **three domains of learning**: cognitive, affective and psychomotor [D3].



It is recommended that simulation-based education be **included as one element** in a blended approach to curriculum development for dementia training [D3].

The **environment**, vicarious and direct **experiences**, **observation**, and **social modeling** promote knowledge, attitudes, empathy, and self-confidence [D5].

Learning opportunities should aim to impact diverse outcomes. Additionally, several opportunities to practice competencies in a **supportive environment** is essential to **decrease distress** [D5].

An association of internationally recognized specialists in the field of dementia is required in order to **review the existing curricula** and to organize them as consistently as possible according to the latest scientific standards [D5].

To ensure holistic perspectives**, a person with dementia** and a **family caregiver** should participate on the development of self-experience interventions [D5].

It should be taken into account that the VDT simulation **may cause anxiety** and stress in the participants [D6].

Direct experience with people with dementia, combined with theoretical knowledge is needed. **Experience** will help students perceive people with dementia holistically and achieve competency in dementia care [D6].

Procedures of performing interventions – time and dose

Self-experience interventions should be **carefully timed** to avoid inconvenient times for participants, e.g. at the end of the semester [G1].

A **repeated** self-experience intervention can reinforce effects [G1].

One-time participation in a dementia simulation program, however, will not be enough for caregivers to maintain newly adopted care strategies. **Caregivers may forget** what they have learned and therefore feel a greater burden in caring for people with dementia. The believe of knowing what to do can be challenging, when there is no way to go down that path [H4].

Preparation of participants

Participants should be **prepared** for self-experience interventions regarding technology, contents etc. [A1, A2].

(8)

Provider

Course facilitators need to develop strong debriefing skills. Working with an **experienced educator** and taking time to practice the skills in a safe environment are recommended [D3].

Instructors should be trained and certified [H8].

Facilitators and barriers

There is always a risk that the impact of any project or intervention can diminish over time [B1]. Moreover, study B1 indicates, that there might be a **lower attendance rate** for an intervention if it is **not mandatory**. Self-experience interventions might therefore be more beneficial if they are part of a mandatory advanced training, for instance.

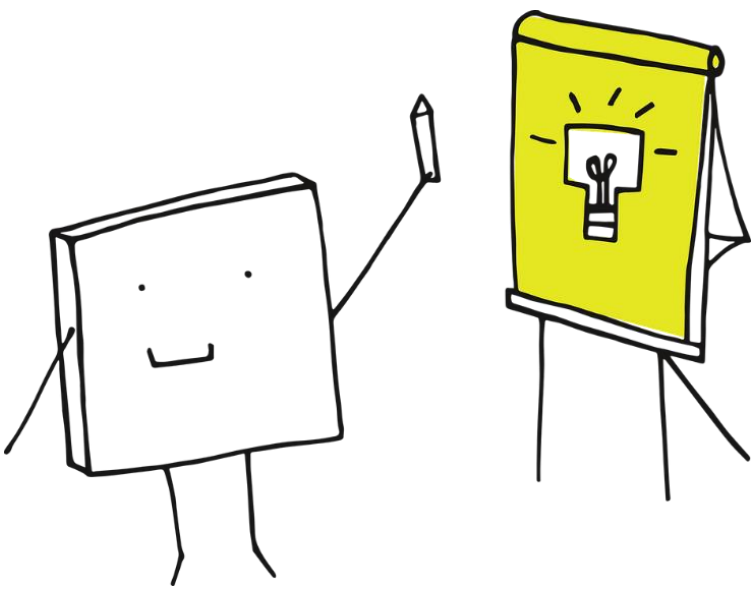
(9)

Senior leadership of the project will be advisable, and the involvement of the whole organisation – all staff at every level, its roll-out over a lengthy timeframe and permanent integration into the organisation within induction, dementia training courses and the intranet [B1]. All staff members should participate on the intervention to gain a common awareness and understanding. If the intervention is mandatory, the importance to the organisation is conveyed and ensured that staff has to be released to attend.

Another important aspect for a successful intervention is the **correct channel of distribution**. Hence, the right channel is to consider intensively [B2].

Participants should have the **opportunity to reflect** on their impressions and feelings arising from the simulation intervention [A2, G1].

Continued education and support programs after having participated in a dementia simulation experience are needed to help caregivers through a successful application of strategies into their daily life [H4]. As dementia progresses further, caregivers may face several different challenges [H4].



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INTenSE

This eBooklet is an outcome of an intensive literature search and the conduction of focus groups. All of the above is supposed to represent the current state of the art regarding self-experience by simulating dementia symptoms. All participants are hopeful that this knowlede will benefit the development of a modern simulation – the INTenSE tool.

Project Management:

MARTIN LUTHER UNIVERSITY HALLE-WITTENBERG

With contributions by:

SOCIALIT SOFTWARE E CONSULTING SRL

DUBLIN CITY UNIVERSITY

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