THE EMOTIONAL EXPRESSION OF PEOPLE WITH DEMENTIA

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Abstract

**Objective:** The number of people that suffer from a chronic disease and need special care increases due to better medical conditions people become older and older. One example of such a disease is dementia. It is one of the most common deadly diseases worldwide. Which makes dementia an important topic for us all. In 2010 the disease already affected 35 million people worldwide.

This systematic review investigates the emotional expression of people with dementia because emotions play an important influence on the quality of life of people with dementia and their caregivers. Specifically, this review examines instruments that can measure emotional expression and with what method researchers of the studies evoked an emotional reaction in their participants. Further it investigates if there are emotions that demented people display more frequently than others and also, if there is a difference between emotion expression in people with dementia and healthy elderly people.

**Method:** For this review four electronic databases (Scopus, Web of Science, PsychInfo and PubMed) were used to scan the following terms “emotion*” AND (“dementia” OR “Alzheimer” OR “mild cognitive impairment”) AND “age*” AND (“expression*” OR “regulation*”). Further only articles that were written in Dutch or English were included. The articles had to focus on people with dementia and not their caregivers or family members and they had to include an instrument that was able to measure an emotional reaction.

**Results:** The different instruments to measure emotional expression and methods used to evoke emotions were compared. In this review six different instruments which can measure an emotional reaction could be found. All of these have their advantages and disadvantages.

In this review all studies focused on facial expression. There are also different methods to evoke an emotional reaction, for example film clips. Other studies observed their participants in their daily routine. Then the outcomes of all 14 studies were compared and a difference was made between studies that used a control group and studies that were more observational.

This review revealed that people with dementia, even in a severe stage of the disease are still able to show a broad range of emotions. There were only minor differences between participants with dementia and healthy controls. One difference seems to lie in the feeling of an emotion and the expression of emotion. These often do not match in people with dementia.

Emotions of people with dementia have an influence on their behavior and the other way around.

**Discussion:** People often think that patients with dementia feel depressed or do not really experience their environment anymore. But this review shows that this prejudice is mostly
wrong. They are able to feel and express their emotions the same way as healthy people do. Their mood or feelings are influence in the same way as ours are. This is especially important for staff members in nursing homes. With this knowledge they can increase the quality of life of their patients and make the rest of their lives a little happier and lifeworthy.
1.0 Introduction

Due to better medical interventions people become older and older (Becker, 2014). Becker (2014) states that most elderly people are still healthy and able to live independently. But also, the number of people that suffer from a chronic disease and need special care increases. An example of such a disease is dementia. It is a disease that affected 35 million people worldwide in 2010 (Wimo, Jönsson, Bond, Prince & Winblad, 2013). The number of affected people nearly doubled every twenty years which means that a lot of resources and money are needed to care for people with dementia.

The most common form of dementia is Alzheimer’s disease (Davey, 2014). It accounts for 50 percent of the people with dementia (Becker, 2014). Becker (2014) also states that at one point of the disease nonverbal communication becomes more and more important for the emotional well-being of the patients. Due to cognitive decline, patients will not be able to communicate verbally in a later stage of the disease (Seidl, Lueken, Thomann, Kruse & Schröder, 2012). However, the interpretation of their facial expression, their gestures and posture can give cues about their well-being and wishes (Re, 2003). Nevertheless, there are only a few studies that investigate changes in facial and verbal expression in patients with Alzheimer’s disease (Magai, Cohen, Gomberg, Malatesta & Culver, 1996).

The current systematic literature review investigates the role of emotional expression in Alzheimer’s disease. In order to give more background information, the symptoms of Alzheimer’s disease, its course and its causes will be explained. Moreover, the term “emotion” will be clarified. Also, the functions of emotions and their expression and how they can be measured will be explained. At last, there will be an explanation about why it is important to focus on emotional expression when working with patients that suffer from Alzheimer’s diseases.

1.1 What is Alzheimer’s Disease?

As mentioned earlier Alzheimer’s disease is known as the most common form of dementia (Davey, 2014). It is a fatal, degenerative illness with no cure (Howe, 2008).

What causes the disease? Even though Alzheimer’s disease is the most common form of dementia, only in the past two decades we have been able to identify the causes of Alzheimer’s disease (Davey, 2014). According to Davey (2014), beta amyloid plaques clump together which leads to the death of healthy neurons. Moreover, neurofibrillary tangles (abnormal collections of twisted nerve cell threads) lead to wrong impulses that are send between nerve cells which then leads to their death. These changes finally lead to a gradual
shrinkage of healthy brain tissue. Another factor that might play a role in the development of Alzheimer’s disease could be the neurotransmitter acetylcholine (Davey, 2014). The levels of acetylcholine drop too low which leads to an impairment of several brain functions, like memory loss. According to Barranco-Quintana, Allam, Del Castillo & Navajas (2005) age, sex, genetics, a family history of dementia, a history of head injury, and low educational status are known risk factors for Alzheimer’s disease.

As described before, the disease is characterized by slow but progressive neural damage which will be expressed through cognitive and behavioral impairments (Davey, 2014). Patients will become unable to remember new information, they will have problems solving complex tasks, and their visuospatial abilities and language functions will be severely impaired (Waanders-Oude Elfrink, van Tilborg & Kessels, 2015). Examples of this cognitive decline are forgetting names (especially in the beginning), disorientation or confusion (Davey, 2014). In the end the body of people suffering from the disease becomes so weak that they become bedridden. Other symptoms that frequently occur are aphasia, apraxia, agnosia, impairments of judgement and decision-making (Davey, 2014). It is important to note that semantic and autobiographic memory are preserved longer than recent memory (Fernandez Montenegro, Gkelias & Argyriou, 2017).

In addition to these cognitive impairments, people who suffer from Alzheimer’s disease also often show behavioral changes like a depressive mood, paranoid behavior, anxiety, hallucinations, delusions or apathy (Waanders-Oude Elferink et. al, 2015). Furthermore, some patients show personality changes, can become generally irritable and difficult to control (Davey, 2014).

1.2 What are emotions?
As we have seen emotionality changes during the course of the disease. To appropriately care for people with Alzheimer’s disease the emotional well-being plays an important role, as well as the communications via facial expression, gestures and postures of the body (Becker, 2014). But what are emotions actually?

For decades there have been discussions about what emotions are. Since the beginning of these discussions many models that describe how the mechanisms of emotions work, have been developed (Coppin & Sander, 2016). But still, there is not one specific definition about what emotions are, but there are numerous (Izard, 2010). Kleinginna and Kleinginna (1981) even composed a list of 92 definitions of emotions from different textbooks and journals which can be classified into nine categories (as cited in Izard, 2010). Nevertheless, many
psychological scientists and behavioral neuroscientists agree on the fact that emotions have an impact on our thinking, our actions and decision-making, our relationships with others, our well-being and, also on our physical and mental health (Izard, 2010).

According to Levenson (1999) emotions have several functions. They can modify our attention, activate certain networks in memory, they organize responses of our bodies (facial expression, voice tone etc.) and through emotions we are pushed to or pulled away from certain people, objects or ideas. Darwin states that emotions are survival tools (e.g. fear sharpens our senses) (Coppin & Sander, 2016).

According to Shuman and Scherer (2015) there are three criteria that need to be considered to define emotions. First, emotions are two-stepped processes (triggering an emotion is followed by an emotional response) Second, objects or situations need to be relevant for the individual to elicit an emotion and lastly, the duration of emotions is short, and they have a quick onset. They also state that there are five components that typically characterize an emotion: expression, action tendency, bodily reaction, feeling and appraisal (Coppin & Sander, 2016). That means that longer lasting moods and proclivities or aversions are not included in this definition.

In this review I will limit myself to the component “expression”. Emotional expressions can be divided into facial expressions, vocal expressions, body actions and postures (Coppin & Sander, 2016). According to Matsumoto and Ekman (2009) there are seven universal facial expressions (joy, surprise, contempt, sadness, anger, disgust and fear). These facial expressions of emotions can be labeled as basic emotions (Coppin & Sander, 2016). Coppin and Sander (2016) also state that these expressions either reflect a mixture of valence and arousal or social messages. In order to interpret them, it is important to consider the context of the situation.

Now that it has been described what emotions are and how they can be expressed, the question “how can emotional expressions be measured” arises. For example, Coppin and Sander (2016) state that there exist several tools to measure facial expressions of emotion. There is the Facial Action Coding System (FACS) which was developed by Ekman and Friesen (1971). With this tool the muscle movements that are involved in facial expression can be specified by trained people. Using the electromyography (EMG) is another way to measure facial expressions. This tool measures the activity of muscles that are involved in facial emotional expression. It is also possible to use automated facial image analysis measurement or thermal analysis of facial muscle contractions. Both of these last two techniques are still under development.
Bodily reactions triggered by emotions are to some degree specific for certain emotions (Wallbott, 1998). When people are sad, for example, they are motionless, their head hangs on their chest and they act passively (Darwin, 1872 as cited in Wallbott, 1988). Several approaches exist to measure movement behavior (Wallbott, 1988). An example is the modality approach which provides observers with different with categorial definitions of body movements (Wallbott, 1988). According to Scherer and Wallbott (1985) there are also functional classifications which focus on the functions of body movements. People, also change the volume, tone and pitch of their voice to express their emotions (Scherer, 2005).

1.3 Alzheimer’s disease and emotion

Earlier it has been described what Alzheimer’s disease and emotional expressions are and how these can be measured, but what role do emotions actually play in Alzheimer’s disease? The recognition of emotions as well as the expression of emotions are essential for social communication (Hun, Zayteseva, Bao, Pöppel, Chungm Kim & Kim, 2014). When treating patients with Alzheimer’s disease it is important to keep their quality of life as high as possible for as long as possible (Howe, 2008). Therefore, it is important to create positive emotions by creating good social relationships, using areas of functioning to compensate for functions they may have lost, encouraging them to continue taking on household responsibilities and doing things for them to make life easier (for example switching from buttons to elastic waistbands) (Howe, 2008). Magai et al., (1996) found that emotionality changes when the disease progresses. For example, at a certain point depression or a depressive mood may determine the day of patients with Alzheimer’s disease. This means that understanding emotionality in patients with Alzheimer’s disease is very important for caregivers and patients.

The emotional well-being of people with the disease is significantly influenced by the quality of communication (Rösler, Schwerdt & von Rentelen-Kruse, 2005). That means, as the disease progresses it becomes more and more important for caregivers to communicate nonverbally with their patients because at one point of the disease they will not be able to talk anymore (Seidl et al. 2012). From this it follows that, it is important for optimal person-centered care to carefully read in the faces of the patients or by their bodies what they like or need and what they do not like or need (Becker, Kruse, Schröder & Seidl, 2005). This also means caregivers need to be able to recognize changes in the voice or facial expression (Rösler et al., 2005).
Another important point that needs to be considered when examining emotional expression or changes in these expressions of patients with Alzheimer’s disease, is that the structure of the brain changes. Researchers found that the amygdala and the prefrontal cortex which are involved in emotion are also affected by the disease (Burton & Kasziak, 2006). Emery and Amaral (2000) found that the amygdala has interconnections with neural structures that are crucial for voluntary facial expression whereas the striatum is important for spontaneous facial expression.

The disease also has an impact on the emotional memory. As I mentioned earlier, remote memories in Alzheimer’s disease are preserved longer than recent memory. It is also known that intense emotions make it easier for us to recall events (Tulving, 1987).

Earlier investigations mainly focused on emotion recognition and less on emotion expression (Hun et al., 2014). But some studies showed that demented people are able to express their emotions (Henry et al., 2009; Mograbí et al., 2012). To get an overview of how emotion expression is affected by Alzheimer’s disease, the following research questions will be answered:

Research question 1: What instruments are used to measure emotion expression? And what methods are used to evoke an emotion so that these emotions can be measured by these instruments?

This review tries to investigate what kinds of tools or methods there are to measure emotion expression of people with Alzheimer’s disease respectively dementia. And also, it examines the way in which emotions of the participants in the different studies are triggered. This might have an influence on the outcomes. It is already known that there are several ways to measure emotion expression. But what kind of emotions can be measured through these instruments? Matsumoto and Ekman (2009) for example state that joy, surprise, contempt, sadness, anger, disgust and fear a universal facial expression. This review tries to figure out if the used tool or methods are able to measure these expressions.

Research question 2: What are the correlates of emotion expression and people with dementia? And is there a difference between people with dementia and healthy elderly people?

As we know demented people are able to show a broad range of emotion (Magai et al., 1996). Many studies show that at one stage of the disease some people with dementia become depressed or angry (Magai et al., 1996). But what emotion do they show the most? Is there a
sort of balance between the emotions or is there one that has the superiority? And do demented people differ from healthy controls?
2.0 Method

A systematic review was executed in order to examine the emotional expression of people with Alzheimer’s disease. Figure 1 gives an overview.

Four electronic databases (Scopus, Web of Science, PsychInfo and PubMed) were used to scan the following terms “emotion*” AND (“dementia” OR “Alzheimer” OR “mild cognitive impairment” AND “age*” AND “expression*” OR “regulation*”). If the article was not written in Dutch or English, they were directly excluded. The date of publication was not an exclusion criterion to get a broad overview. The remaining articles were screened on title and abstract. If they fulfilled the criteria the full-text of the article was read.

The number of the first articles that were identified through these databases was enormous (N=929). After removing the duplicates 587 articles remained. Due to this substantial number, only the titles of the articles were screened. From these 587 articles 215 were left for title scanning. Articles were excluded if: 1. the title did not address Alzheimer’s disease or dementia, 2. the title did not address humans, 3. the title focused on other symptoms primarily (e.g. depression etc.), 4. the title did not focus on people with Alzheimer’s disease (e.g. caregivers, nurses etc.) and 5. the title explicitly mentioned that they were using an emotion recognition task. If the title was too vague the articles were kept for abstract scanning.

As a result, 120 articles remained. The abstracts of these 120 articles were then scanned. The articles were excluded if: 1. the study did not address humans with Alzheimer’s disease or other forms of dementia, or elderly, or emotion, 2. the study used a recognition task and 3. the study primarily focused on medical or biological issues. 95 articles were excluded which left 78 articles.

These 78 articles were left for full-text scanning because the abstracts of the other articles focused too much on emotion recognition or emotion processing. For example, Lupu-Stanescu (2015) focused on how patients with Alzheimer’s disease process emotions and how that might influence their social behavior or their behavior in general. Other studies like the one from Kang (2012) examined the social behavior of demented people and how the understanding of it could help caregivers to better care for these patients and consequently increase their quality of life. The study from Klein-Koerkamp, Beaudoin, Baciu and Hot (2012) investigated the emotional decoding abilities of patients with Alzheimer’s disease. This was also not the purpose of this review, so studies like that were excluded.
The full-text of the remaining 78 articles was read. The articles were excluded if the study focused on family members, caregivers etc. because the aim is to find out how demented people express emotions and not on how other would rate this ability. One example is the study from Tappen and Williams (1998). The participants of the study (family and staff members) were interviewed about how patients of a nursing home with Alzheimer’s disease express their feelings. The researchers did not interview the patients directly. The study was therefore excluded.

Other articles were excluded if the study did not include a method that measures emotion expression or if the study focused on medical or biological questions. The study of Wong, Cronin-Golom and Neargarder (2005) for example, examined the ability of emotion recognition of demented people and not emotion expression. This was a reason to exclude the study. Ogrocki, Hills and Strauss (2000) investigated the eye movement patterns of people with Alzheimer’s disease. Ragneskog, Asplund, Kihlgren and Norberg (2001) tried to reduce typical symptoms like agitation or shouting, that people with Alzheimer’s disease often show, through music. These two studies are examples of studies that focus more on medical or biological questions than on emotion expression which excluded them from the systematic review.

The full-text of two articles (Smith, 1995; Asplund et al., 1991) could not be found. In the end 14 articles remained for the systematic review.

Then the characteristics of the participants were further investigated. Which form of dementia do they suffer from and what stage are they in. Also, the age, the number of participants, the gender, the place of living (e.g. nursing home) and the countries where the study took place in were examined.

Next the different instruments that measure emotional expression, but also the instruments that measure cognitive impairment of the patients, were listed and defined. It was also recorded if the study was more observational or experimental and how often and how long the participants were tested. For example, did they use a control group of healthy participants or were researchers simply observing everyday behavior.

At last the outcomes of the studies were examined. A difference was made between studies that used a control group and studies that did not. It was presented what the different studies did, what instrument they used and how they evoked emotions of the participants. Then the results were presented as follows: first the studies that used a control group were compared and second studies that did not use one and were therefore more observational were described.
Figure 1. Flowchart Identification of Researches. (Moher, Liberati, Tetzlaff, Altman, & Group., 2009)
3.0 Results

14 studies fitted the criteria to be included in this systematic analysis (Lee et al., 2017; Chen et al., 2017; Lee et al., 2015; Takayanagi et al., 2014; Lee et al., 2014; Lee et al., 2013; Mograbi et al., 2012; Mograbi et al., 2012; Seidl et al., 2012; Hammar et al., 2011; Henry et al., 2009; Burton and Kaszniak, 2006; Magai et al., 1996 and Asplund et al., 1995).

3.1 Participants

Table 1 gives an overview of the participants of the studies that are included in this systematic review. Together the studies included 1002 participants of which 691 participants were female and 241 were male. Two studies (Takayanagi et al., 2014 and Burton and Kaszniak, 2006) did not mention the sex of the participants. They included the remaining 70 participants. The number of participants varied from 4 to 226.

The participants in seven studies suffered from Alzheimer’s disease. In one study there were participants suffering from Alzheimer’s disease and also participants suffering from Frontotemporal dementia or another neurodegenerative disease. In the remaining six studies the term dementia was used instead of naming a specific form.

In seven studies participants lived in nursing homes. In two studies participants were selected from a dementia clinic, in another study from a day therapy center and an aged care hostel. The other four studies did not mention where they selected their participants.

The age of the participants in these studies varied from 57 years to 89 years. In six studies the age was stated as 65 years and older. One study (Takayanagi et al., 2014) stated the age as 84 and older. In another two studies (Seidl et al., 2012 & Asplund et al., 1995) some participants were younger than 65 years. One study (Chen et al., 2017) did not mention the age of participants.

Six studies were executed in the USA, two in England and Sweden. One study was executed in Australia and one in Germany. In one study (Takayanagi et al., 2014) the country was not mentioned.
<table>
<thead>
<tr>
<th>Author</th>
<th>N</th>
<th>Form of dementia</th>
<th>Gender in %</th>
<th>stage</th>
<th>place of living</th>
<th>age in years</th>
<th>country</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lee et al. (2017)</td>
<td>110</td>
<td>-</td>
<td>73</td>
<td>mild-severe</td>
<td>nursing home</td>
<td>65 and older</td>
<td>USA</td>
</tr>
<tr>
<td>Lee et al. (2015)</td>
<td>177</td>
<td>-</td>
<td>76</td>
<td>mild-severe</td>
<td>nursing home</td>
<td>65 and older</td>
<td>USA</td>
</tr>
<tr>
<td>Lee et al. (2014)</td>
<td>36</td>
<td>-</td>
<td>77</td>
<td>mild-severe</td>
<td>nursing home</td>
<td>65 and older</td>
<td>USA</td>
</tr>
<tr>
<td>Lee et al. (2013)</td>
<td>30</td>
<td>-</td>
<td>73</td>
<td>mild-severe</td>
<td>nursing home</td>
<td>65 and older</td>
<td>USA</td>
</tr>
<tr>
<td>Seidl et al. (2012)</td>
<td>45</td>
<td>AD</td>
<td>79</td>
<td>-</td>
<td>-</td>
<td>64-69</td>
<td>Germany</td>
</tr>
<tr>
<td>Hammar et al. (2011)</td>
<td>10</td>
<td>VD; AD</td>
<td>60</td>
<td>severe</td>
<td>nursing home</td>
<td>66-92</td>
<td>Sweden</td>
</tr>
<tr>
<td>Magai et al. (1996)</td>
<td>82</td>
<td>AD</td>
<td>77</td>
<td>-</td>
<td>nursing home</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Asplund et al. (1995)</td>
<td>4</td>
<td>AD</td>
<td>50</td>
<td>severe</td>
<td>-</td>
<td>57-89</td>
<td>Sweden</td>
</tr>
<tr>
<td>Chen et al. (2017)</td>
<td>226</td>
<td>AD, FTD, NC</td>
<td>77</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>USA</td>
</tr>
<tr>
<td>Takayanagi et al. (2014)</td>
<td>36</td>
<td>-</td>
<td>-</td>
<td>moderate/severe</td>
<td>nursing home</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Mograbi et al. (2012a)</td>
<td>23</td>
<td>AD</td>
<td>61</td>
<td>mild-moderate</td>
<td>-</td>
<td>65 and older</td>
<td>England</td>
</tr>
<tr>
<td>Mograbi et al. (2012b)</td>
<td>43</td>
<td>AD</td>
<td>69</td>
<td>mild-moderate</td>
<td>-</td>
<td>65 and older</td>
<td>England</td>
</tr>
</tbody>
</table>
3.2 Methods

All studies had different aims that they tried to reach. But all included either triggers or situations that evoke emotions and the measurement of emotional expression. Moreover, all studies used different instruments to measure the emotion expression of the participants. To answer research question one (1. What instruments are there to measure emotion expression? 2. What methods are there to evoke an emotion?). The instruments that were used in the different studies were examined and their mode of operation was defined. Further the study design was examined to see how the emotions of the participants were triggered. An overview is displayed in table 2 and 3.

Instruments used were the ODAS, FACS, EMFACS, EEB. Other studies either used the Observed Emotion Rating Scale (OERS), Electromyography (EMG) or the Maximally Discriminative Facial Movement Coding System (MAX). One study used two evaluators with practical training in the range and classification of evaluation behavior.

3.2.1 ODAS

Four studies used the Observable Display of Affect Scale (ODAS; Vogelpohl & Beck, 1997). The ODAS was developed to empower people to code videotaped emotional expressions of people who are cognitively impaired (Lee et al., 2015). Lee et al. (2015) state that it consists of 34 behaviors including six subscales. Positive emotional expression consists of four positive facial displays, seven types of positive verbal expressions, and six positive body movements or postures. Whereas negative emotional expression consists of four negative facial displays, eight negative verbal contents and six negative body movements or postures (Lee et al., 2015). The presence or absence of behavior can be coded by trained researchers who were provided with a description beforehand (Vogelpohl & Beck, 1997).

3.2.2 FACS

Two studies (Mograbi et al., 2012b & Asplund et al., 1995) used the Facial Action Coding
System (FACS). The FACS was originally developed by Ekman and Friesen (1978) and is purely descriptive (Sayette, Cohn, Wertz, Perrott, & Parrott, 2001). With this instrument trained coders can nearly identify all possible facial expressions (Ekman and Rosenberg, 1997). It works as follows, people watch film clips which should trigger a specific emotion and are recorded on video. These videos are then watched by the coders who decompose the facial expressions into Action Units (AU’s) (Sayette et al., 2001). 44 AU’s can be discriminated (Ekman and Rosenberg, 1997) such as AU1: inner brow raise or AU 23: lip tightener (Mograbi et al., 2012). Coan and Allen (2007) describe AU’s as “the smallest discriminable facial movements”. Ekman and Rosenberg (1997) state that with the FACS it is also possible to code the intensity of emotions and the timing of facial action. According to them the FACS can be utilized in two ways to measure facial expression. The first one is the FACS interpretation. By that they mean that a computer program (FACS/EMFACS emotion dictionary) is used to classify the FACS-coded facial expressions into emotion and non-emotion categories. The other way is the EMFACS (emotional facial action coding system)

3.2.3 EMFACS

The EMFACS was used in two studies of this systematic review. One of these studies (Seidl et al., 2012) additionally used a self-report questionnaire. The difference between the FACS and the EMFACS is that when using the EMFACS the coder watches everything in real-time and not on video (Ekman and Rosenberg, 1997). Also, when using the EMFACS only AU’s or AU combinations that are unique for certain emotion expressions are included.

3.2.4 EEB

Two studies (Chen et al., 2017; Henry et al., 2009) used the Expressive Emotional Behavior (EEB) Coding System and a self-report questionnaire. The EEB Coding System was developed by Gross and Levenson (1993). It consists of eleven codes (alertness, blinks, body movement, disgust, face touching, happiness, looking around the room, mouth movement, overall facial movement, smiles and yawn). According to Gross and Levenson (1993) blinks, smile and yawn were frequency measures and the others were continuous measures from which the intensity, duration and frequency can be coded.

3.2.5 OERS

The OERS is a rating scale to measure the facial expression of people with dementia (Oppikofer, 2008). Oppikofer (2008) states that it consists of three negative affects (anger, anxiety/fear and sadness) and two positive affects (pleasure and general alertness). The extent
or the duration of the emotions can be rated over a ten-minute period (Lawton, Van Haitsma & Klapper, 1999). Also, the possible signs of these emotions are listed.

### 3.2.6 EMG

The EMG measures the activation of facial muscles by using surface electrodes or intramuscular (Farina & Negro, 2012). According to Wolf, Mass, Ingenbleek, Kiefer, Naber and Wiedemann (2005) specific muscle patterns used to show disgust, appetite, relaxed joy and aroused joy can be identified through this instrument. In The study of Burton & Kaszniak (2006) the acidity of the corrugator supercili muscle (knits eye brows together) and the zygomaticus major muscle (pulls lips back and up) were measured with the EMG.

### 3.2.7 MAX

The MAX codes movement changes in three facial regions: the forehead, the eye brows and the mouth (Matias, Cohn & Ross, 1989). Trained researchers are needed in order to code the videotaped material (Magai et al., 1996). According to Matias et al. (1989) the MAX provides measures of negative, positive, and intermediate affective expression.

To evoke emotions in the participants different methods were used. In twelve studies the participants were videotaped, and their emotion expression was later analyzed.

### 3.2.8 Film clips

Several participants were videotaped while watching emotional arousing film clips. In fact, 3 studies (Chen et al., 2017; Mograbi et al., 2012a; Henry et al., 2009) used film clips in order to evoke an emotional response in their participants. These film clips were either positive, negative or neutral.

### 3.2.9 IAPS

Others were videotaped while looking at pictures from the International Affective Picture Systems (IAPS) that were either positive neutral or negative. The IAPS provides a set of color pictures that is supposed to evoke emotions (Lang, Bradley & Cuthbert, 1997). It includes pleasure arousal and dominance ratings and is used to examine emotion and attention of people (Coan & Allen, 2007).

### 3.2.10 Family visit, care situation

In the studies from Hammar (2011), Magai (1996) and Asplund (1995), participants were videotaped during their daily routine or a family visit.
3.2.11 PARO
One study (Takayanagi et al, 2014) compared a baby seal robot (PARO) to a stuffed animal in form of a lion to trigger an emotional response in their participants while they were being videotaped. PARO has four senses (sight, sound, balance & touch) and it is able to respond to contact by movement or making noises (Robinson, MacDonald Kerse & Broadbent, 2013). It was invented to be an alternative for pharmacological treatment in dementia (Takayanagi et al. (2014). According to Takayanagi et al (2014) it had already shown reducing effects on stress, anxiety and pain.

3.2.12 Success-failure manipulation
Mograbi et al. (2012b) developed two success-failure manipulation computerized paradigms, one based on reaction time, one based on memory. In the paradigm based on reaction version one time a warning tone appeared and after a few milliseconds a care came up. Participants had to stop the car as soon as it came up by pressing a button. In version two the participants had to catch a ball that fell from a building by pressing the button. In the paradigm based on memory version one, one to ten everyday objects were spread on the screen. The participants had to point to the same object in the same sequence as it was done by the computer before. In version two they had to listen to a sequence of digits (0-9) which was also presented on the screen. Then they had to repeat the sequences verbally.

3.2.13 Studies without videotaping
One study did not videotape their participants (Burton & Kaszniak, 2006). In that study the emotional expression of the participants was directly measured by an EMG while they were looking at pictures from the IAPS which was developed to evoke different emotions, either positive, neutral or negative.

3.2.14 ToM Eyes Test
Henry et al. (2009) used the Mind in the Eyes test (ToM-Eyes test) in addition to film clips that were supposed to trigger different emotions. According to Henry et al. (2009) the ToM-Eyes test uses 36 pictures of eyes to index Theory of Mind (ToM). Participants look at the pictures and select out of four words which describes the feelings or thoughts that these eyes express best (Henry et al., 2009). This was done to see if participants are able to recognize emotions in others.

3.2.15 Cognitive impairment
Half of the studies used the Mini Mental State Examination (MMSE). This test is normally used to measure cognitive impairment, find out about changes in cognitive functioning over
time or see if therapeutic interventions have worked (O’Bryant, Humphreys, Smith, Ivnik, Graff-Radford, Petersen & Lucas, 2009). Seven studies did not use it. From these, five did not use any tool to measure the cognitive impairment of the participants. Other tests that were used to measure cognitive impairment were CERAD memory test, NPI, AES, BCRS and FAST. One study (Asplund et al., 1995) used autopsy after the patients died to confirm the diagnosis of Alzheimer’s disease.

3.2.16 Other

In three studies the Geriatric Depression Scale (GDS) was used additionally to other tests. It allows to find out about depressive symptoms in elderly people (Sheikh & Yesavage, 1986). Lee et al. (2017; 2015) used the Cumulative Illness Rating Scale for the accumulated evaluation of illnesses (Miller & Towers, 1991). Magai et al. (1996) used the Adult Behavior Questionnaire in order to measure affect in people with dementia.

Table 2

Methods

<table>
<thead>
<tr>
<th>Author</th>
<th>Procedure</th>
<th>Instrument measuring</th>
<th>Cognitive impairment</th>
<th>Other instruments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lee et al. (2017)</td>
<td>videotaped between 8AM &amp; 8PM</td>
<td>ODAS</td>
<td>MMSE</td>
<td>CIRS-G</td>
</tr>
<tr>
<td>Lee et al. (2015)</td>
<td>videotaped between 8AM &amp; 8PM</td>
<td>ODAS</td>
<td>MMSE</td>
<td>CIRS-G</td>
</tr>
<tr>
<td>Takayanagi et al. (2014)</td>
<td>PARO or lion; videotaped 2 evaluators with practical training in range &amp; classification of evaluation behavior</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Lee et al. (2014)</td>
<td>videotaped between 8AM &amp; 8PM</td>
<td>ODAS</td>
<td>MMSE</td>
<td>Typology from Martino-Saltzman et al. (1991)</td>
</tr>
<tr>
<td>Lee et al. (2013)</td>
<td>videotaped between 8AM &amp; 8PM</td>
<td>ODAS</td>
<td>MMSE</td>
<td>-</td>
</tr>
<tr>
<td>Seidl et al. (2012)</td>
<td>IAPS + videotaped</td>
<td>EMFACS + SRQ</td>
<td>MMSE</td>
<td>GDS; Hachinski</td>
</tr>
<tr>
<td>Study</td>
<td>Methodology</td>
<td>Measures</td>
<td>Ischaemic Score</td>
<td></td>
</tr>
<tr>
<td>-------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
<td>---------------------------------</td>
<td>-----------------</td>
<td></td>
</tr>
<tr>
<td>Hammar et al. (2011)</td>
<td>videotaped during ‘ordinary’ morning care and MTC</td>
<td>OERS, MMSE, RTCS; MTC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Magai et al. (1996)</td>
<td>videotaped during 20 min family visit</td>
<td>MAX, medical charts, ABQ; GDS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asplund et al. (1995)</td>
<td>videotaped during 5 selected caregiving situations</td>
<td>FACS + UNM, DSM-3, autopsy</td>
<td>Scale of Reisberg et al. (1985); category G of Katz's index</td>
<td></td>
</tr>
<tr>
<td>Chen et al. (2017)</td>
<td>3 film clips; videotaped</td>
<td>EEB + SRQ, CDRS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mograbi (2012a)</td>
<td>4 film clips; videotaped</td>
<td>EMFACS + SRQ</td>
<td>MMSE, CERAD memory test, Agnosia Questionnaire for dementia</td>
<td></td>
</tr>
<tr>
<td>Mograbi (2012b)</td>
<td>2 SFM computerized paradigms; videotaped</td>
<td>FACS</td>
<td>MMSE, CERAD memory test, OJD</td>
<td></td>
</tr>
<tr>
<td>Henry et al. (2009)</td>
<td>4 film clips; videotaped</td>
<td>EEB</td>
<td>DSM-4</td>
<td></td>
</tr>
<tr>
<td>Burton &amp; Kaszniak (2006)</td>
<td>IAPS</td>
<td>EMG + SRQ, MMSE</td>
<td>GDS</td>
<td></td>
</tr>
</tbody>
</table>

**Note:** CIRS-G = Cumulative Illness Rating Scale-Geriatric; SRQ = Self-report Questionnaire, RTCS = Restrictiveness To Care Scale; MTC = Music Therapeutic Care, ABQ = Adult Behavior Questionnaire, GDS = Geriatric Depression Scale, CDRS = Clinical Dementia Rating Scale, OJD = Objective-Judgement Discrepancy
3.3 Study design

Half of the studies were experimental which means they were either compared to a control group or different interventions were used to see if there are differences between the tested groups. The other half was more observational. They simply observed the behavior of the participants without including a control group.

Table 3 provides an overview of how all of the studies were executed, if a control group was used and how long and how often the participants were observed and also if the study was more observational or more experimental.

In eight of the studies, participants were tested and observed only once. In the studies of Lee et al. (2017, 2015, 2014 & 2013) they were observed 12 times once per hour for 20 minutes on 2 days. Takayanagi et al. (2014) tested their participants twice. Each time for 15 minutes. The intervals between the testing sessions were three to six months long. Participants of the study from Hammar et al. (2011) were observed four times once a week during ordinary morning care and four time once a week with an intervention called “Music therapeutic caregiving” (MTC).

Six of the studies used healthy control groups to compare their outcomes to people who suffer from dementia. The study of Takayanagi et al. (2014) compared people with mild dementia to people in a severe stage of the disease. Chen et al. (2017) included not only people with Alzheimer’s disease and healthy controls, but also people suffering from other forms of dementia. The other eight studies (Lee et al., 2017, 2015, 2014 & 2013; Seidl et al., 2012; Hammar et al., 2011; Magai et al., 1996; Asplund et al. 1995) did not include a control group.

Table 3

<table>
<thead>
<tr>
<th>Author</th>
<th>Study design</th>
<th>Control group</th>
<th>Duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lee et al. (2017)</td>
<td>observational</td>
<td>-</td>
<td>observed 12 times once per hour on 2 days</td>
</tr>
<tr>
<td>Lee et al. (2015)</td>
<td>observational</td>
<td>-</td>
<td>observed 12 times once per hour on 2 days</td>
</tr>
<tr>
<td>Lee et al. (2014)</td>
<td>observational</td>
<td>-</td>
<td>observed 12 times once per hour on 2 days</td>
</tr>
<tr>
<td>Takayanagi et al. (2014)</td>
<td>observational</td>
<td>moderate vs. severe dementia</td>
<td>observed twice; intervals 3-6 months</td>
</tr>
</tbody>
</table>
Lee et al. (2013)  observational  -  observed 12 times once per hour on 2 days
Seidl et al. (2012)  observational  -  observed once
Hammar et al. (2011)  observational  -  observed once a week for 8 weeks
Magai et al. (1996)  observational  -  observed once
Asplund et al. (1995)  observational  -  observed once

Chen et al. (2017)  experimental  healthy; different forms of dementia  observed once
Mograbii et al. (2012a)  experimental  healthy  observed once
Mograbii et al. (2012b)  experimental  healthy  observed once
Henry et al. (2009)  experimental  healthy  observed once
Burton & Kaszniak (2006)  experimental  healthy  observed once

3.4 Outcomes
To answer research question two, the outcomes of all 14 studies were compared. A difference was made between studies that used a control group and studies that did not. Nine studies did not include a control group. Results can be found in table 4.

Lee et al. (2017, 2015, 2014 & 2013) investigated different aspects that could influence emotional expression of people with Alzheimer’s disease. In one study they examined the influence of social interactions (presence of social interaction/ verbal / non-verbal / both in social interaction / and quality of social interaction) on demented people (Lee et al., 2017). In this study they found that the presence of positive and neutral social-interaction increases the
expression of positive emotions significantly \((p < .01)\) whereas the presence of social interaction did not have a significant effect on negative emotional expression at a 0.05 level. According to Lee et al. (2017) verbal interaction significantly increases positive emotional expression. Non-verbal interaction alone did not have this effect. But together (verbal & non-verbal interaction) they increased positive emotional expression of the participants \((p < .01)\). They also found that verbal and non-verbal interactions were associated with an increase in negative emotional expression \((p < .01)\). Moreover, they found a significant association between positive a neutral interactions and positive emotional expression. When the quality of interaction was positive or neutral, the expression of positive emotions increased. In contrast to that a neutral or negative quality of interaction had the inverse effect. Also, a higher score on the MMSE predicted a lower negative emotional expression.

In another study Lee et al. (2015) investigated the connection between emotional expression of people with Alzheimer’s disease and pain. To do so, they used the ODAS to measure facial expression. Also, trained coders asked the participants one direct question (“Are you in pain?”). They then examined any verbal or non-verbal cue that could be a “yes” or a “no”. They found that 97% of the participants were able to respond to the question, even if they were in a moderate or severe stage of the disease. Moreover, people with Alzheimer’s disease do express more negative emotions, when they have lower scores on the MMSE. This study also revealed that the presence of pain is associated with greater negative emotional expression.

Lee et al. (2014) examined the wandering behavior of people with dementia. Participants were observed twelve times a 20-min once per hour between 8 AM and 8 PM. Wandering was defined by the typology from Martino-Saltzman et al. (1991). Lee et al. (2014) found that positive emotions and lower scores on the MMSE are associated with an increase in wandering whereas negative emotions have the inverse effect.

In another study from Lee et al. (2013) they investigated the daytime emotional expression of people with dementia. They found out about several different things. Smiling and a relaxed facial expression were most frequently observed for positive emotional expression whereas a negative body posture or repetitive body movements were most frequently observed for negative emotional expression. Lee et al. (2013) also found that women express more positive and negative emotions than men, and the older the demented person gets, the more does he or she express negative emotions. But participants with a college degree or higher expressed less
negative emotions than participants with a junior high school education or lower. According to them severity of the disease does not have an influence on their emotional expression. All in all, Lee et al. (2013) found that people with dementia showed a broad range of emotions, even in a later stage of the disease and that they show more positive emotions (13.51, SD = 12.49) than negative emotions (1.57, SD = 2.26).

Takayanagi et al. (2014) investigated if the baby seal robot PARO has a psychological effect on participants with severe dementia compared to participants with moderate dementia and if the introduction of PARO can improve the willingness of the staff to work on interventions for demented people. They found that the participants with moderate dementia reacted with more positive affect to PARO than to the lion they showed as a control. Specifically, they found that participants showed greater frequency of talking, positive emotional expressions and that they were laughing more often while interacting with PARO than with the lion. Takayanagi et al. (2014) came to the conclusion that PARO was accepted as a pet and that it reduced loneliness more than the lion did. Compared to that, participants with severe dementia did not talk more frequently to PARO than they did with the staff members but showed less neutral reactions to PARO than to the lion. This study also revealed that PARO facilitated the start of a conversation with the demented participants, not matter what stage they were in.

Seidl et al. (2012) investigated the determinants of emotional facial expression in Alzheimer’s disease. Therefore, they used pictures from the IAPS to elicit emotions. What they found is that the increase of the rate of total facial expression is associated with cognitive deficits. Apathy controls the influence of cognitive deficits on facial expressions and apathy correlates significantly with a decreased overall and specific facial expression. They concluded that apathy has a specific influence on facial expression in Alzheimer’s disease, namely increased apathy leads to less overall and less facial expression. They also came to the conclusion that cognitive deficits are connected with a loss of specific facial expression.

Hammar et al. (2011) examined the influence of “music therapeutic caregiving” (MTC). According to them MTC has a positive influence on the expression of positive emotion and the expression of general alertness. 22% of the participants expressed pleasure (including singing, whistling, smiling & laughing) for more than one minute during ordinary care whereas 50% of the participants expressed pleasure for more than one minute during care with MTC. 72-5% of the participants expressed pleasure while the caregiver was singing. These findings were significant (p < .016). Anger was not shown longer than five minutes.
during MTC intervention. Also, anxiety or fear decreased during the intervention. Sadness was shown the least during both caring situations (75% in ordinary care, 85% during MTC intervention expressed no sadness). General alertness (participating in task, eye contact, looking around & responding) significantly increased (p < .042). Moreover, MTC reduces resistance of patients during morning care and increases positive emotional expression.

Magai et al. (1996) found that participants with Alzheimer’s disease show interest, happiness, fear, sadness and anger even in a severe stage of the disease. During the middle and late stage of the disease the expression of emotion does not vary much. But joy seems to be lower in a later stage of the disease than at the beginning. Also interesting is that family members and staff members sometimes reported different emotions in different stages. For example, staff members reported a decline in sadness between stage six and seven whereas family members reported no change (Magai et al, 1996).

The last study (Asplund et al., 1995) investigated on people in the last stage of dementia. The study was very small (N=4). It compared the FACS to the unstructured naturalistic method (UNM). The result of the study was that also people in a late stage of dementia are able to express emotion through their faces. They did not specify which emotions they could observe.

Table 4

Outcomes observational studies

<table>
<thead>
<tr>
<th>Author</th>
<th>tested situation</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lee et al. (2017)</td>
<td>social interaction*</td>
<td>social interaction &gt; nonsocial interaction**</td>
</tr>
<tr>
<td>Lee et al. (2015)</td>
<td>self-repot pain</td>
<td>&gt;pain &gt; neg. affect</td>
</tr>
<tr>
<td>Lee et al. (2014)</td>
<td></td>
<td>&gt;PEE &gt; wandering</td>
</tr>
<tr>
<td>Takayanagi et al.</td>
<td>PARO</td>
<td>&gt;PEE, social interaction, laughing</td>
</tr>
<tr>
<td>(2014)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lee et al. (2013)</td>
<td>observation in daily living</td>
<td>PEE &amp; NEE in advanced stage of disease</td>
</tr>
<tr>
<td>Seidl et al. (2012)</td>
<td>pictures from IAPS (pos./ neg./ neut.)</td>
<td>&gt;apathy &gt;spec. FE</td>
</tr>
<tr>
<td>Hammar et al. (2011)</td>
<td>MTC</td>
<td>MTC &lt; resistance</td>
</tr>
</tbody>
</table>
Magai et al. (1996) family visit show broad range of emotions

Asplund et al. (1995) care situation show broad range of emotions

Note: *with staff members **for positive affect
Note: PEE= positive emotional expression; NEE= negative emotional expression; FE=facial expression

The five studies that compared participants with Alzheimer’s disease to elderly people who did not suffer from dementia found minor differences between the groups, if at all. The results can be seen in table 4.

Chen et al. (2017) investigated the subjective experiences of non-target emotions in people with Frontotemporal dementia and Alzheimer’s disease compared to healthy controls and people with another neurodegenerative disorder. This was the only study that gave an overview about different emotions which were not just defined as positive or negative. They did that by letting the participants watch different 3 film clips to evoke different target-emotions (amusement, sadness and disgust) and by letting them fill in self-report questionnaires with seven non-target emotions (affectionate, afraid, angry, ashamed, embarrassed, enthusiastic and proud) and the three target emotions (amused, disgusted and sad). They found that demented people experience a broad range of emotions. Specifically, they expressed amusement, sadness, disgust, anger, fear and embarrassment. Table 5 provides an overview. In the self-report questionnaire people with Frontotemporal dementia and Alzheimer’s disease did not differ from the control groups in experiencing non-target facial expressions. Chen et al. (2017) found that the only thing that distinguishes them from the control groups is that people with Frontotemporal dementia and Alzheimer’s disease report to experience more mixed emotions when watching emotionally arousing film clips. They also found that participants with Alzheimer’s disease seem to experience more positive non-target emotions than participants with Frontotemporal dementia. But although people with Frontotemporal dementia and Alzheimer’s disease report that they experience more non-target emotions than healthy controls, they did not display more of these emotions than people from the healthy control group while watching the film clips.

Mograbi et al. (2012a) found that people with Alzheimer’s disease reacted appropriately to film material that was emotionally salient. They let the participants watch four film clips (1 neutral, 1 positive and 2 negative) whereas the positive film clip was always shown last. Also, they let participants fill in a self-report questionnaire. What they found is that the reactivity
indicated by facial expressions showed little differences compared to healthy controls. But the
control group showed a broader range of facial expressions and also, more intense reactions to
emotionally arousing film material. As we have already seen in the study from Chen et al.
(2017) the results from the self-report questionnaires and the expressed emotion also
differentiate. Mograbi et al. (2012a) found that participants with Alzheimer’s disease report in
the questionnaires less reactivity to the Alzheimer and the cancer film (both negative films)
for happiness, fear and hopelessness whereas there were no differences compared to the
control group in their facial expression. The results from the questionnaire and the videotaped
material were the same for the neutral and positive films. Which means that the answers from
the questionnaire are conform to the facial expression participants made while they were
watching the positive or the neutral film clip.

In another study of Mograbi et al. (2012b) they examined the emotional reactivity during
performance failure of people with Alzheimer’s disease and healthy elderly. For that they
developed two success-failure manipulation computerized paradigms. One was based on
reaction time, the other on memory. The result of the study was that people with Alzheimer’s
disease and healthy controls displayed more intense emotion when they failed. But in contrast
to healthy controls, participants with the disease showed reduced awareness of performance.
That means it was difficult for participants with Alzheimer’s disease to differentiate between
success and failure. Mograbi et al. (2012b) suggest that this might be due to a dissociation
between performance judgement and a persevered emotional reactivity to failure.

Henry et al. (2009) let their participants watch 4 film clips (2 neutral, 2 amusement). The
neutral film clips were always shown first to establish baseline emotional responding. The
amusement films were shown counterbalanced. One of these clips was supposed to evoke a
spontaneous emotional reaction. The other film was shown with the instruction to either
suppress or show their emotions. The participants were told to either suppress their feelings or
to show them (suppression or amplification). Henry et al. (2009) found that participants with
Alzheimer’s disease showed lower positive affect than healthy controls when they were
instructed to amplify their emotions. In this study people with Alzheimer’s disease also
showed reduced expressive flexibility of emotion which indicates an inability to regulate
displaying emotions to different external demands. Moreover, they found that both groups,
even participants in a moderate to severe stage of the disease, are able to inhibit current
emotion-expressive behavior.
Burton and Kaszniak (2006) investigated on the zygomaticus major muscle of people with Alzheimer’s disease and healthy controls. This muscle pulls the lips back when people smile (Fridlund & Cacioppo, 1986, cited in Burton & Kaszniak, 2006). The also focused on the corrugator supercili muscle (knits eye brows together). For that they used pictures from the IAPS (24 positive, 24 neutral and 24 negative) to evoke an emotional reaction. They used EMG to measure the muscle activity. They also used a self-report questionnaire. Their findings showed that healthy controls did differ from people with Alzheimer’s disease. Demented participants showed minimal zygomatic activity while viewing positive valanced images. This was inverse for healthy controls. But it is interesting that when they viewed negative valanced images, participants with the disease and also, participants from the control group showed maximal zygomatic activity. Burton and Kaszniak (2006) also found differences in the self-report questionnaires and the actual facial expression of participants with Alzheimer’s disease. They did not explicitly mention where these differences were found.

Table 5

<table>
<thead>
<tr>
<th>Studies with control group</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Author</strong></td>
</tr>
<tr>
<td>Chen et al. (2017)</td>
</tr>
<tr>
<td>Mograbi et al. (2012a)</td>
</tr>
<tr>
<td>Mograbi et al. (2012b)</td>
</tr>
<tr>
<td>Henry et al. (2009)</td>
</tr>
<tr>
<td>Burton &amp; Kaszniak (2006)</td>
</tr>
</tbody>
</table>

*Note. *for the cancer and Alzheimer’s film **while viewing positive images.

ME= mixed emotion; SFM= success-failure manipulation; EE= emotion expression
<table>
<thead>
<tr>
<th></th>
<th>Amusement film clip</th>
<th>Sadness film clip</th>
<th>Disgust film clip</th>
</tr>
</thead>
<tbody>
<tr>
<td>FTD</td>
<td>+</td>
<td>-</td>
<td>/ +</td>
</tr>
<tr>
<td>AD</td>
<td>+</td>
<td>-</td>
<td>/</td>
</tr>
<tr>
<td>NC</td>
<td>+</td>
<td>-</td>
<td>/</td>
</tr>
<tr>
<td>HC</td>
<td>+</td>
<td>-</td>
<td>/</td>
</tr>
</tbody>
</table>

*Note: + = amusement; - = sadness; / = disgust*
4.0 Discussion

To get an overview about what instruments there are to measure emotional expression in people with dementia, how these work and what emotions demented people are able to express, 14 studies were analyzed. In the following the research questions will be answered and the results will be discussed.

To answer research question one (1. What instruments are there to measure emotion expression? 2. What methods are there to evoke an emotion so that these emotions can be measured by these instruments?) the different instruments to measure emotional expressions and methods used to evoke emotions were declared and compared. In these 14 studies six different instruments were used to measure emotional expression, namely the ODAS, the FACS, the EMFACS, the EEB, the OERS, the EMG and the MAX. All these instruments measure the facial expression of emotion and not other modalities like body movement or voice.

To evoke an emotional response in their participants film clips, pictures from the IAPS, baby seal robot PARO or success-failure computerized paradigms were used, or they were simply observed during normal living in their nursing homes, a family visit or during caring activities. Except for Burton and Kaszniak (2006), all studies videotaped their participants and analyzed their emotional expression later.

The limitations of the different instruments used to measure facial expression have to be considered. The FACS for example does not rate the color of the face and it does not rate the movements of pupils which are also indicators of emotional expression (Asplund et al., 1995). Due to this, studies that used the FACS could have missed some emotional expression of their participants. Only few information can be found about the EEB in literature which makes it difficult to say anything about its reliability. Studies that used the MAX, FACS and EMFACS needed trained coders. So, experts are needed in order to execute research with these instruments.

From the 14 studies that were included in this systematic review, the ODAS was the most used instrument (four times) to measure emotional expression. All of these studies took place in the same nursing homes and were executed by the same authors. But the studies were executed in different years. Thus, they could have included the same sample group which might have had an impact of the results from these studies.

The EMG measures the activation of facial muscles (Wolf, 2015). But only specific emotions (disgust, appetite, relaxed joy and aroused joy) can be measured (Wolf, 2015). That means that studies which used this method were not able to identify other emotions like anger or
sadness. This might have influenced their results. According to Lawton, Van Haitsma, Perkson and Ruckdeschel (1999) the reliability and validity of the OERS are good.

To answer research question two (1. Which emotions do people with dementia express that can be measured with these instruments? 2. Is there a difference between people with dementia and healthy elderly people?) the outcomes of all 14 studies were compared and a difference was made between studies that used a control group and studies that were more observational.

From all these studies it became clear that people with dementia are able to display different kinds of emotion, even in a severe stage of the disease. Either positive or negative. These findings were the same for studies that were executed in natural situations and studies that used different methods to evoke an emotional reaction. Studies that were more observational, especially the studies from Lee et al. (2017, 2015, 2014 & 2013) found correlations between emotion expression and different things like social interaction, pain, wandering, education and sex. This leads to the conclusion that emotional expression is systematically related to different factors. These findings can be underlined by what was mentioned by Rösler et al. (2005) in the introduction. For example, they state that social interaction plays an important role in the quality of life of people with dementia.

Mograbi et al. (2012b) found that people with dementia can recall emotions of failure better than emotions that are less intense. These findings agree with Tulving (1987) who states that it is easier for us to recall events that are emotionally arousing. That means people with dementia memorize emotionally arousing events the same way, as healthy people do.

Unfortunately, there were only two studies (Chen et al., 2017; Magai et al., 1996) that specifically named the emotions that participants expressed. All other studies used the terms positive emotion expression and negative emotion expression. It also became clear that people with dementia only show minor differences in their facial expression of emotion, if at all, compared to healthy elderly people. But one major difference seems to lie in the expression of emotion and the experience of emotion. The results from the self-report questionnaires that some studies used deviated from the emotions that were measured by the instruments for participants with dementia, but not for healthy participants. This would also mean that when demented people are asked about their feelings this might lead to different results, compared to what instruments analyzing the facial expression of emotion would measure.

Chen et al. (2017) suggest that the fact that participants with Frontotemporal dementia and
Alzheimer’s disease report to experience more non-target emotions than they actually express, could be due to alterations in somatic and / or autonomic emotional responding, the production and processing of interoceptive information, or due to a deception of social and contextual cues. Mograbi et al. (2012a) argue that the subjective loss of reactivity to emotional arousing material, whereas facial expressions were preserved could be based on the fact that cognitive degeneration and emotional reactivity are resided in different areas of the brain. Future studies could use self-report questionnaires about the emotional state of their participants after they were watching emotional arousing film clips, looking at pictures or during other situations. And also analyze their emotional expression while they are watching these, for example with the instruments mentioned in this review. These outcomes then can be compared. On top of that it would be interesting to figure out if there are any differences between healthy participants and participants with dementia.

Some other studies in this review also state that the areas in the brain where emotional processes take place and where dementia causes cognitive damage are not the same. That is why people with dementia, even in a late stage of the disease, are able to feel and express emotions appropriately. One of these studies which supports this hypothesis is the one from Magai et al. (1996). They mention the discrete emotions theory (Izard, 1991; Izard & Malatesta, 1987; Magai & McFadden, 1995) whereupon the system responsible for emotions is separated from other psychological systems, like cognition. This would mean that people with dementia are still able to express their emotions because this area of the brain is, to a greater or lesser extent, protected against the disease. Another example is the study from Lee et al. (2013). They refer to Eldridge, Masterman and Knowlton (2002) who state that the key brain areas for emotional processing (basal ganglia and amygdala) are relatively protected from neural degeneration. But as mentioned in the introduction Burton and Kaszniak (2006) state that other researchers found that the amygdala and the prefrontal cortex which are involved in emotion are also affected by the disease. Other studies about brain areas that are affected by dementia need to be read to resolve this problem.

As we can see from the results of Chen et al. (2017) and Magai et al. (1996), the range of emotions that people with dementia are able to show is similar to healthy elderly people. Most of the studies did not find any differences between healthy controls and participants with dementia. But, as mentioned earlier only these two studies presented specific emotions that the participants displayed. All other studies only evaluate the emotions as positive or negative. Therefore, it does not become clear if there are emotions that demented people show more
frequently. Moreover, if we look at the results we can see that all studies had different research questions. The results have to be considered with regard to this fact.

In addition to that, all studies, except for Lee et al. (2017, 2015, 2014 & 2013) were executed in different nursing homes. This means that it is difficult to transfer these results to people who do not live in nursing homes. So, it would be interesting to examine if emotional expression, respectively the frequency of specific emotions, distinguishes if participants were not living in nursing homes but in familiar environment. This becomes more important because more and more people stay at home until they die. Also, important to notice is that some studies had very few participants, for example Asplund et al. (1995) who only examined four participants. These results could be coincidence. But there were also large studies (Chen et al. 2017) with 226 participants that got similar results than these smaller studies. Therefore, even these small studies seem to be reliable. Some of the studies did not have a control group which means we do not know if healthy elderly people would react the same way. Future studies are needed to fill this gap.

Considering the large number of articles (929) that came up at the beginning of this review, it has examined a broad range of what was already done in the field of emotion expression in dementia. Using the terms “dementia”, “Alzheimer” and “mild cognitive impairment” ensured that the whole field of dementia was covered. Because the date of publication was not an exclusion criterium, all studies investigating this field were screened. Even though all studies used different instruments to measure emotion expression the outcomes are very similar which makes the results of this review reliable.

This review also showed that a lot of research was done, for example, on emotion recognition in dementia, but less on emotion expression: only 14 articles were included. Another explanation why only a small number of studies was included is that some articles that could have been interesting for this review could not be found.

An interesting limitation of this study is that all studies in this systematic review focused on facial expression of emotion and not on other ways to express emotions like language or body movements or postures, although the search terms were held very broad. As mentioned earlier in the introduction, Matsumoto and Ekman (2009) state that there exist seven universal facial expressions of emotion (joy, surprise, contempt, sadness, anger, disgust and fear). Which means that emotional expression could be hereditary and might therefore be difficult to disappear. This might be an explanation why demented people are still able to express their emotions appropriately through their faces. Another explanation why all studies focused on the facial expression of emotion could be that linguistic and motoric abilities of people with
dementia decrease while the disease progresses (Magai, Auer, Reisberg, Sclan & Cohen, 1992). Therefore, it would be difficult to get information of the emotional status of people with dementia if they are not able to express these via language or their body.

Another reason why all these studies focused on facial expression of emotion and not on other ways could be the search terms that were chosen for this systematic review. These did not include terms like “verbal” or “body”. But on the other hand, the term “facial” was not used either, and still, all studies of this review focused on this term. Future reviews should include these terms to see if they come to different results. Because all the studies only focused on the facial expression of emotion and did not include verbal or movement behavior this review could not show if demented people are also able to use these modalities appropriately.

Other limitations of this review are that it could not give an answer to the question if there are emotions that people with dementia show more frequently. This question could not be answered because almost all studies investigated positive and negative emotions but did not specifically name these. Earlier in the introduction it was said that demented people often become depressed or angry (Magai et al., 1996). But, what can be seen from these results is that people with dementia do not only feel sad or depressed. In fact, they are able to feel and express different kinds of emotions.

The fact that some studies had the same authors needs to be considered because this could have had an influence on the outcomes or the interpretation of the outcomes.

In conclusion, this review was able to answer all research question except for the question if there are emotions that people with dementia show more frequently. It gives a good overview about what instruments can be used to measure facial expression of emotion and about how people with dementia express their emotions through their faces. It showed that people with the disease express their emotion through their faces in a similar way healthy elderly people do, and also that their emotion expression is systematically related to different factors, like pain or gender. Unfortunately, this review was not able to show how people with dementia express their emotions through other modalities than their faces.

As mentioned in the introduction dementia is a neurodegenerative disease which cannot be healed and will end in death (Davey, 2014). For the clinical practice the findings of this review mean that we can provide good care for demented people without pharmacological means but with the help of different non-pharmacological techniques like PARO or MTC. This also means that social interaction plays an important role for a happy life with dementia. In practice that means that caregivers should encourage these people to participate in social
activities with for example other nursing home residents. This review also revealed that patients with Frontotemporal dementia and Alzheimer’s disease may report feelings that are not conform with their facial expression which makes it difficult for caregivers to find out what their patients really want. It also shows that different things, like pain have an influence on the mood of people with dementia but also that their mood has an influence on different things, like wandering. This review made clear that people with dementia may not be able to express themselves verbally at one point of the disease, but that they still express their emotion in the same way as healthy people do.

In summary, because dementia and especially Alzheimer’s disease it one of the most common diseases that affects elderly people all over the world (Wimo et al., 2013) and also their families and caregivers, we need to make sure that they get the best care they can. Logsdon and Teri (1997) state that enjoyable events are protective against depression in dementia. As mentioned in the introduction, many of us have the prejudice that demented people are mostly depressive and that they do not really experience their environment anymore (Magai et al., 1996), but considering the results from this review, they are still able to display and a broad range of emotions even in a severe stage of the disease. This knowledge can be used to increase the quality of life of people with dementia and make the end of their lives a little happier and lifeworthy. Also, understanding how demented people feel and react will make caring for them a lot easier.
5.0 References


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