“Your husband went fishing”

A literature review on lying in communication by caregivers with older people who have memory disorders

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Abstract:	

The aim of this research is to raise awareness on the use of lies and withhold of truth in daily communication by caregivers with older adults who have memory disorders.

Two research questions were created to fulfil the aim by conducting a literature review: 1. How is the appropriateness of lies in daily communication used by caregivers with older people who have memory disorders argued? 2. What are the factors that make lies acceptable?

The theoretical frame used in this research is Carl R. Rogers person-centred approach which is also the foundation of Tom Kitwood's person-centred dementia care. Ten scientific articles were collected through the search engines EBSCO, SAGE and ScienceDirect and analyzed using content analysis. Limitation of this study was that the topic is highly controversial and ethically sensitive, as it raises a lot of expert opinions but only a few scientific researches of high quality are published.

The results are that caregivers use lies mostly with good intention on their mind in order to enhance well-being, out of a lack of alternatives or in order to cope with caregiver burden. The truth was considered to be distressing and truth-telling was found to be restricted by higher instances in care ward hierarchy or family members of the client. Different factors, such as the person lying, the person being lied to and the lie itself influence the acceptability of the act. There are no clear agreements about what constitutes a lie in dementia care and its general acceptance in the care context. Even though the lie was found to be person-centred if certain factors are being met, the topic remains ethically sensitive.

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Tämä tutkimus käsittelee hoitajien valheiden käyttöä hoitoapuna ihmisille joilla on muistihäiriöitä. Tavoitteena on nostaa asia esille ja lisätä tietoisuuttaa.

Aiheesta esitettiin kaksi tutkimuskysymystä: 1.Miten asianmukaista on valehtelemisen kommunikoidessa arkipäiväisessä hoidossa ja kuinka sen käyttöstä väitellään ? 2. Mitkä seikat vaikuttavat valehtelun hyväksymiseen?

Teoreettinen viitekehys on Carl R. Rogerin henkilökeskeisen lähestymistapa, joka pohjautuu Tom Kitwoodin henkilökeskeisen dementian hoitoon. Kymmenen artikkelia on valittu elektronisia kirjallisuuden hakukoneita käyttämällä: Ebsco, Sage ja Science direct. Artikkelit on analysoitu sisältöanalyysin avulla. Tätä tutkimusta on vaikeuttanut se, että aihe on erittäin kiistanalainen ja eettisesti herkkä. Asiantuntijat esittävät aiheesta herkästi mielipiteitä, mutta tieteellisiä tutkimuksia on julkaistu vain vähän.

Hoitajat käyttävät valheita heidän mielessään pääsäntöllisesti hyvässä tarkoituksessa, koska vaihtoehdot puuttuvat tai keinona työtaakan keventämisenä. Totuuden katsottiin olevan tuskallista ja sen kertomista on rajoitettu hoito-osaston hierarkian tai perheenjäsenen kautta. Hyväksyttävyyteen vaikuttavat eri seikat, kuten henkilö joka valehtelee, henkilö jolle valehdellaan ja valhe itse. Ei ole selkeätä käsitystä siitä, mitä valhe tarkoittaa dementiahoidossa ja onko se yleisesti hyväksyttävä. Vaikka valheen todettiin olevan tietyllä tavalla henkilökeskeinen, aihe pysyy edelleen eettisesti herkkänä.

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1 INTRODUCTION

During her studies the author of this work gained work practice in a long-term care ward for older people with memory disorders. Situations such as a resident saying "No thanks, I will eat later at home" were witnessed, whilst later meeting the same person at the door trying to leave the ward calling "I am going home now. Thanks for everything!" In Finland doors of care wards are often locked and stop the person already at the attempt of leaving. But what if they would not be? How do caregivers respond to someone with a memory disorder in situations he or she is disoriented to time and place? Is it better to tell the truth to the resident about retirement and living in a care home due to cognitive impairment, or is it better to invent reasons why he or she should not leave?

There are two reasons for studying this topic: James et al. (2006) surveyed staff working in care settings and found that lying is a pervasive strategy used: only four of the 112 participants responded that they never lied, only two said neither them nor their colleagues lied. That is as little as 3.6% and 1.8% respectively of the respondents. Older people with memory disorders have special needs and caregivers need to be highly trained for giving the necessary support (Pool 2007 p.27). By considering that the use of lies in elderly care is pervasive and little researched and knowing that communication skills are a crucial factor in care, implicates the need to give special attention to this theme.

2 BACKGROUND

The following quote summarizes a caregiver's experience on communication:

> I was in a Nursing Home (caring for a) woman who had Alzheimer's and she said: "Oh, where is my husband?" and I had been told that this lady had been a widow for about 15 years and I'd looked at this women and said to her: "Oh sweetie, your husband died 15 years ago" and the woman's grief was instantaneous. It was like I was delivering the news for the first time about her husbands death and I felt devastated...and I thought, "Oh my God, now I have this mourning woman…" and in hindsight…if that ever happens to me again I might just say: "He's out in the garden or he's gone away or he'll be back" only because I know that they'll forget about it in a couple of minutes…If you delivered the truth to (the Alzheimer patient) it might be really devastating for them …I mean, I have never forgotten about that…I think I might just divert them and not answer the question next time (Tuckett 1998 p.296).

In this example conversation leads to feelings of confusion and helplessness on part of the caregiver and emotional pain on part of the woman with Alzheimer's. The author considers

the way of responding to older people with memory disorders as immensely important when providing good quality care and sees a lack of available literature. This research is intended to contribute to already published material on communication and to offer support in challenging situations such as the one described above by the nurse in Tuckett (1998 p.296).

Communication got into focus of this thesis, because it is considered to be crucial on the bottom of caregiving. If there is insufficient knowledge or inconstancy about the way to respond, some caregivers may choose to lie, some other tell the truth or distract and the cumulative effect of these varied approaches may result in increased confusion, distress and a possible loss of trust on part of the older person (Phair & Good,1995, p.79).

2.1 Aim and research questions

The aim of this research is to raise awareness on daily communication by caregivers with older people living with memory disorders by highlighting the act of telling lies. In this literature review the following two research questions are going to be answered by collecting data and analyzing content:

1. How is the appropriateness of lies in daily communication used by caregivers with older people who have memory disorders argued?
2. What are the factors that make lies acceptable?

After an initial search on the theme it appeared that the topic raises highly controversial arguments. The debate about the use of lies in care for older adults with cognitive impairment started around 2006 in the Journal of Dementia Care. Research question one “How is the appropriateness of lies in daily communication used by caregivers with older people who have memory disorders argued?“ was chosen to collect and sort the arguments mentioned in available research in a structured way in order to get an overall view on the debate. It appeared that lying as a phenomenon gets acceptable according to the individual situation. Therefore the second question investigates the circumstances that lead to acceptability of lies. The conditions that lead to acceptability at the same time determine the context for a lie being unacceptable, as both are connected strongly.

2.2 Memory disorders and care

Memory disorders summarize a variety of diseases that damage the brain due to chronic progressive degeneration of nerve cells. This damage is caused by conditions such as Alzheimer's, vascular dementia, lewy body dementia, frontotemporal dementia and others. Some researchers summarize these conditions as 'dementia', or refer to the most common 'Alzheimer disease' in their work, but in this thesis the term 'memory disorders' or 'cognitive impairment' is used.

'Memory disorders' as a syndrome affects memory (especially short-term memory), orientation (time, place and person), communication, personality and behavior (Adams 2008 p.2). The receiving, storing and processing of information is altered as well as expression and action (Jacques & Jackson 2000 p.107). According to the specific diagnosis different symptoms appear in specific combinations and every person with a memory disorder is an individual and therefore unique (Buijssen 2008 p.19 ff.). That means that if a caregiver seeks to understand a person with memory disorders, it is crucial to consider the person's speech as unique, influenced by for example personality (Killick & Allan 2001 p.126).

In this thesis the term 'Dementia care' is used to express assistance older people with a memory disorder need in daily life. Kitwood recognized the need to change attitudes and care cultures in dementia care and calls on memory disorders to be seen as a form of disability rather than a destroyed personality and identity during the course of the disease. The quality of care is a crucial factor determining how a person with a memory disorder is affected. Caregiving should be seen in a more positive light in order to enrich the account of dementia, whereas in the old culture words and actions of people with that condition were seen as a breakdown in mental processes and ignored (Kitwood 1990 p.177, 1997 p.136).

If a caregiver wants to fully understand the person with a memory disorder he must assume that words and actions do **always** have meaning, even though it is difficult in some occasions to interpret and understand that meaning (Killick & Allan 2001 p.125). Örulv (2010 p.40) and Sachweh (2008 p.44 f.) suggest that in adjustment to linguistic and cognitive abilities people with memory disorders need to be involved in a constructive dialogue to help them make sense of the environment.

2.3 Lying by caregivers

In the following paragraph the concept of lying is described. Lying is an intentional act, so someone without that intention may give false statements, but was not lying. Withholding or hiding information can be lying too, but it requires that information was withheld intentionally. In cases that information was forgotten to tell about, it does not count as lying (Vrij 2000 p.5 f). Lies are part of deception and defined as *"a successful or unsuccessful deliberate attempt, without forewarning, to create in another a belief which the communicator considers to be untrue"* (Vrij 2000 p.6).

Different types of lies

According to Vrij (2000 p.10) it is distinguished between outright lies, exaggerations and subtle lies. Outright lies are those submitting information completely contradictory to the truth. Exaggerations are extensions to the truth. Subtle lies are designed to mislead, for example by concealing information or withholding relevant details. In the context of dementia care it is found that the definition of lies is not quite clear. Some researchers regard 'keeping the mouth shut' as in withholding the truth as lying whilst others include only clear incidents of treachery as lies (Mitchell et al. 2007 p.24, Walker 2007 p.28).

Kitwood views outright lies (a total falsehood), trickery or dishonest representation as *treachery*, in cases used to force a person into compliance. The case of a woman with memory disorders illustrates his understanding of treachery:

> Mrs. D, a childless widow, has no close relatives in the district. Her neighbour reports that she is behaving oddly, and wandering in the street at night. Her nearest relatives, who live some way away, are asked to intervene. They visit her, and tell her that they are going out for a drive, as they have often done. The drive ends up at the geriatric assessment ward of the local mental hospital, and she is admitted. (Kitwood 1990 p.181 f.)

This example shows how an older lady is deceived in order to admit her into long-term care without involving her own will. Richard Taylor, a popular author and activist has Alzheimer himself and describes a similar case to this one. After being deceived the victim felt deeply disappointed by this incident and stated she could never forget how her children betrayed her (Taylor 2009 p.15 f. in appendix 1 case E).

Svenja Sachweh (2008 p.267 f.), a linguist and communication coach describes ‘white lies’ as makeshift in distressing care situation. According to her the caregiver respects the point of view and the needs of the confused person and puts own understanding of right and wrong behind by taking the perspective of the older person. Her understanding of ‘white lies’ seems equal to Vrij’s understanding of ‘subtle lies’.

Bender (2007 p.12) suggests distinguishing between lies of omission (not correcting a false impression) and lies of commission (uttering an untruth). He also differentiates lies used by people with power inequalities or in relationships that power is roughly equal. In relationships that power is unequal distributed and the lie is utilized to inhibit informed decision making, a lie is clearly abusive.

Why do people lie?

Lying is part of a normal repertoire of interacting with other people in our social environment. It only becomes morally wrong, once lies are used to cheat or abuse others. The variety of reasons to choose a lie is huge and needs further examination. The reasons for caregivers utilizing lies may not be as simplistic as it seems (Bender 2007 p.12). So what makes caregivers respond in certain ways to their client or family members who has a memory disorder? Kitwood explains the structure of each interaction as follow (fig. 1): Person 1 and Person 2 have both unique personalities, are in particular states (having specific moods, emotions, feelings etc.), define the situation in a certain way and have individual desires, expectations and intentions. If Person 1 makes an action, Person 2 is going to interpret this action and respond whereupon Person 1 interprets the response of Person 2 and reflects on that interaction. Person 2 for example wonders whether Person 1 has understood correctly and whether the action is successfully completed (Kitwood 1997 p.88).

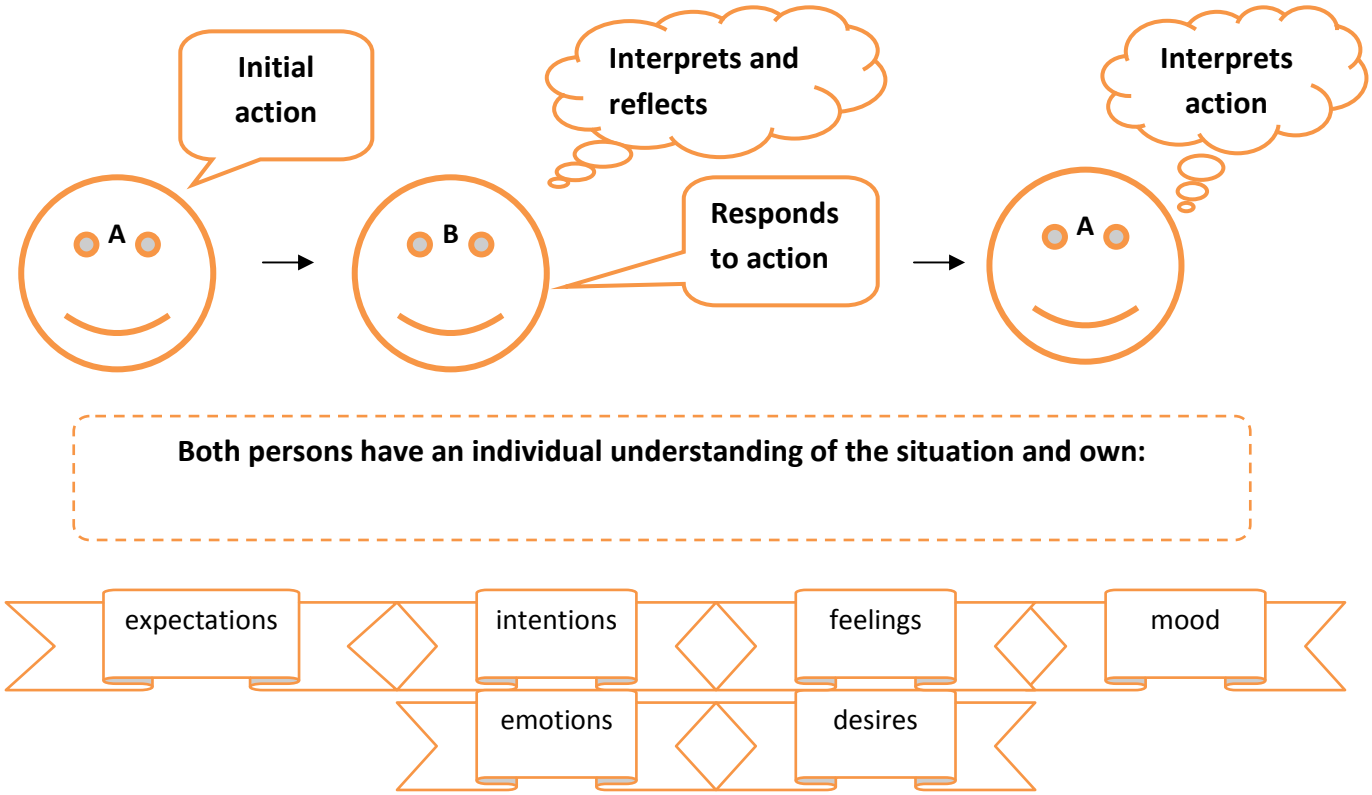

Figure 1: Triadic interaction model

In care context Kitwood (1990 p.185) refers to business and pressure many caregivers are facing. Especially family caregivers carry heavy burdens in their lives when coordinating care; they are often exhausted and suffer from depression which influences their possibility to deliver care. In professional care, a staff level is one factor that influences good quality care. Another reason for lying to a person with memory disorder might be that those people are discriminated in their personhood. Status of the person is lowered and respect and value decreased if negative thinking in terms of personhood exists. An example for such thinking can be found in Dunham (2008 p.49) in which a caregiver states the following: *"But you have to remember that body is not who the person is. The person is gone."* As a possible consequence the person could be treated in inappropriate ways.

Sachweh describes several situations in which white lies are used and justified: In situations the person with memory disorders made a mistake (the lie upholds dignity), confuses a caregiver with somebody else (the lie promotes well-being), in situations the person is sad

and for example missing close relatives (the lie helps to orientate), when experiencing hallucinations (the lie calms down) or when about entering dangerous situations (the lie promotes physical well-being). When using this approach a caregiver must respond empathically and respectfully. Biographical knowledge is necessary to fit the response into the experienced reality of the older person with memory disorders (Sachweh 2008 p.270). Concrete examples of situations in which white lies may be utilized are presented in Appendix 1.

The use of lies in dementia care is criticized from many experts in the field. One recent article on lying published suggests that nurses shall avoid lying in order to avoid potential legal implications (Culley et al. 2013 p.39). Also Rüsing (2009 p.6) for example points out that it is necessary to respond carefully in communication and to avoid thoughtless action. A caregiver for example may withhold the son's death from an older lady with a memory disorder; so that she may settle down emotionally and sleep better. It remains disputable whether her well-being is promoted by helping her to get sleep but not letting her know about her son's death. A caregiver may not always meet the best interest, because it is very difficult to decide for someone else about what is best for that person. Schermer (2007 p.16) holds against by saying that people with cognitive impairment have a different capacity to deal with truth. A healthy person can handle for example painful truth over time by mourning, accepting, and struggling. A person with a memory disorder on the other hand experiences the painful truth continuously as new information and has no capacity to deal with it likewise. But as new information does not change that older person's outlook on life, plans and goals anymore, the truth loses significance.

Schermer (2007 p.16) suggests that in order to lie to somebody it requires that the person has a capacity to form and hold beliefs about what is true and what is wrong. Once a person cannot anymore distinguish between reality and illusion or fact and fantasy it becomes impossible to lie to that person. Such as it is impossible to lie to a baby, it gets impossible to lie to people with memory disorders in advanced states. The point that this capacity is lost comes at some point during the course of the progressive disease, but it is a complex task to assess the awareness of people with memory disorders.

2.4 Ethics of Dementia care

According to Phair & Good (1995 p.158) there are at least two reasons why ethics become important in this matter: First they may provide a framework that helps to react appropriately in individual situations, and second people's awareness can be raised about own values and attitudes. Principles, codes of practice or practice guidelines do not provide ready solutions for every moral dilemma at hand. The Nuffield council on bioethics (2009 p.104 f.) published practical guidance on ethical issues within dementia care and concludes that the difference between telling the truth and using a lie is often not clear in practice. The lie may breach trust, but if the person with memory disorder does not believe in the truth being real, this equally threatens the value of trust.

The following ethical principles and theories are important to consider in dementia care: The principle of autonomy is about respecting an individuals' right to make own choices depending on personal values and beliefs. This principle is difficult to implement in practice if the person is constrained internal due to a memory disorder cognitively. Overriding a client's choice is called paternalism. Beneficence and nonmaleficence are related principles meaning to do good (to benefit) and to avoid harm. Veracity is the fundament of trust and defined as the principle of telling the truth and not to lie or deceive others (Fry & Johnstone 2008, p.22 ff., Phair & Good 1995 p.160). Utilitarianism is commonly translated as something being useful. Deciding whether actions are morally right depends on their balance of bad and good consequences. In the theories of deontology moral rightness is determined by certain rules or principles. For a deontologist for example lying can be wrong independent of consequences (Beauchamp & Childress 1983 p.20 f., p.33, Fry & Johnstone 2008 p.17).

3 A PERSON CENTRED APPROACH AS THEORETHICAL FRAMEWORK

The theory that is chosen to complement the theme of communication is Carl R. Rogers person centered approach. The author chose this approach, because implementing Rogers' ideas into care specialized for older people with memory disorders seems to be an ideal basis for meeting the person behind the cognitive impairment. The core of Roger's theory is that a

growth-promoting climate acts positively on relationships and personal development, which eventually increases the quality of care.

In a study conducted by Edvardsson et al. (2010 p.2614) the core element of person-centered care was identified to be 'promoting a continuation of self and normality'. The memory disorder as a disease interrupts the way life used to be. Good care supports the person to continue life as normal as possible, and details respect, an appreciation of the person as valuable and competent, and opportunities for decision-making about own matters. Amongst other things it was also found to be fundamental to know the persons history, interests, preferences and particularities of the person receiving care. This knowledge needs to be actively used and implemented into care practice.

Rogers found that three factors are crucial in order to establish a growth-promoting environment: empathy, congruence and acceptance. Tom Kitwood's dementia care approach builds up on Rogers' theory and his findings will be used to enrich this theory of person centeredness (Kitwood 1997, Rogers, 1967).

Empathy

"To sense the client's inner world of private personal meanings as if it were your own, but without ever losing the 'as if' quality…" that is empathy described by Rogers (1967, p.92 f.). According to some people it is impossible to obtain a feeling of how it must be to have a memory disorder, without direct experience of that condition (Killick & Allan 2001 p.128). Kitwood (1990 p.184) states that high levels of empathy and imagination are needed in care for people with memory disorders. It requires to be there for the person with an understanding and helping that differs a lot from caring for a person with healthy mental competences. People resist to put themselves in someone else's shoes, because if they see life in someone else's way they are running the risk of being changed themselves. They prefer to view the other person's world only in their terms and analyze and evaluate it from distance. But if they truly understand how it feels and how it is to be another person without losing the separateness of their identity, then change is likely to occur. Sometimes it may seem hard to be empathic with a person. But already the attempt of trying to be empathic communicates value on that individual and that his or her feelings and meanings are considered *worth* of understanding (Rogers 1967 p.93).

Congruence

Congruence after Rogers (1961 p.33) is an awareness of own feelings rather than presenting a façade while holding something back at a deeper level. It is the willingness to be and to express feelings and attitudes from the inside out. He argues that it is better to be as authentic as possible, even with negative feelings to come up such as annoyance, boredom or dislike. It is important for the care worker to constantly listen to their inner voice, reflecting in them what is going on, and sharing their thoughts or acting on them. Rogers (1967 pp.90-92) stresses that this quality of a relationship is probably the most important one, even though it seems often difficult to achieve. Ward et al. (2008 p.639 f.) found that because people with memory disorders are much attuned to emotions of others, caregivers aim in having a stable and positive effect on their clients. The care worker becomes the ever-smiling person such as in flight attendants and this is considered as incongruent behavior after Rogers.

Acceptance

Growth and change of the relationship between a caregiver and the older person is more likely to occur in cases that the caregiver exerts a warm, positive and acceptant attitude towards the client. The client is respected unconditionally for what he or she is, for whatever behavior he or she is showing (Rogers 1967 p.94). It has been found that positive attitudes towards people with memory disorders increase their well-being and the quality of care. Attitudes can be influenced positively by trainings and staff education (Kada et al. 2009 p. 2384 ff.). Norbergh et al. (2006 p.271 f.) suggest that the well-being of caregivers increase in that way as well. When caregivers perceive the older people they take care of as unique and valuable, caregiving itself is valued as very important task

4 METHODOLOGY

This study is a literature review and it seeks to summarize the available amount of literature given for the topic. Its aim is to develop new insights (Aveyard 2010 p.6). After formulating a research question the literature review is a process including the steps 1) finding relevant literature, 2) assessing its quality, 3) extracting relevant data and finally 4) analysing this data in order to develop new knowledge. These steps are carried out in a clear and understandable manner, so that the work could be repeated by someone else reaching a similar conclusion

(Griffiths 2009 p.102). The aim of a literature review is to put together puzzle pieces of scientific research in order to complete a new jigsaw with new insight on the matter (Aveyard 2010 p.6).

The literature review was chosen out of various reasons. Using lies in communication with older people who have memory disorders is an ethically sensitive topic. Using already published data is a way of maintaining a certain distance, which could not be uphold if new data was to be collected. The topic is also very controversial, so that the collection of published data and its analysis is a means to gain new insight. Last but not least the choice of a literature review has personal and practical reasons: no approval by an ethical committee needs to be obtained and the author also felt more familiar and skilled with the chosen method compared to others.

4.1 Inclusion criteria

The scientific articles that are going to be included in this research need to fulfill certain criteria in order to answer the research questions and to contribute to a literature review of high quality. Table 1 summarizes that articles must be relevant to the research topic, available in full text and peer reviewed. The selection criteria includes articles published between 2008 and 2013, but after an initial search it became apparent that this criteria led to only limited hits of scientific articles published with this scope of research. It was decided to include relevant scientific articles of good quality published any time. Excluded are all articles that are not peer reviewed, unavailable as full text or written in any other language than English. Other excluding criteria are that the article is not scientifically written, has no abstract, no method, aim or results and that is not based on evidence.

Table 1: List of inclusion criteria

Inclusion criteria
Articles written in English
Articles available in full text
Articles with abstract, aim, method and results
peer reviewed scientific articles published in subject relevant journals

4.2 Data collection

Initially the author started to search data electronically using different kinds of online databases that could be accessed via the library of Arcada. Table 2 shows the words that were used as search terms in these databases. The scope of this literature review is lying in daily communication used by caregivers with older people that have memory disorders and that are dependent on some amount of care. Included are caregivers that work professionally in the care sector as well as family caregivers. Excluded is communication by older people themselves or communication by physician who disclose a diagnosis to their patients. Table 2 shows all search terms that cover the topic under its aspects and presents all terms that can be used interchangeably.

Table 2: Summary of search terms

Search terms
Alzheimer*(’s disease), dementia, memory disorder*, cognitive impairment
lying, deception, deceiving, truth, lies, truth telling, withholding truth
communication, interaction
caregiving, staff, nursery home, care

Search terms were combined in different variations and typed into electronic databases that access scientific articles. If there were too many hits scored more terms were added in order to narrow the search down, and if there were too little hits terms were taken off to broaden the search so that the chance of missing relevant articles is minimized. Databases that hit suitable articles were Ebsco, Sage journals and Science direct. The term ‘memory disorder’ hit only a few results, because most of the researchers use either the term ‘dementia’ or

'Alzheimer's', therefore the search was adapted accordingly. By searching articles electronically it was possible to find seven suitable scientific articles. The final result of the electronic search is presented in table 3.

Table 3: Summary of the electronic search process

Database	Search terms	Total no. of hits	Articles chosen
Ebsco	lying and dementia	61	1
Ebsco	deception and Alzheimer's	10	4
Sage journals	truth telling and dementia (abstract)	2	1
Science direct	truth-telling and dementia and communication	320	1

A secondary search increases the chances to find relevant data. Besides electronic search the author also hand searched the reference lists of relevant articles, searched by author and table of contents in theme-related journals. It was possible to identify three more articles by hand searching and author searching the articles that were already chosen. Ten articles in total were collected and are presented in table 4.

Limitations

The topic of lies and deception used by caregivers in daily communication is not well researched yet, and therefore the biggest limitation was to retrieve scientific articles of good quality. As this topic is quite controversial dementia care specialists have been debating in relevant journals a lot, but research studies with clear aim and method are rare to find. One way to cope with this challenge was to include also those articles that were published any time. Another challenge was that some relevant material was difficult to assess. The library collection of the metropolitan area of Helsinki and the electronic material available are limited, thus limiting accessible material. The author coped with that challenge by loaning one book used in the background as interlibrary loan. Another solution to access research material was to contact authors of scientific articles and organisations that subscribe to relevant journals to send a copy of the article in demand.

Reliability and Validity

The term reliability in research context means that the process can be repeated by anyone else reaching same conclusions (Kumar 2011 p.181). Validity after Kumar (2011 p.184) means that the chosen research instrument is used to find out what it was designed for. A research is valid if the study establishes a logical link between research questions and the objectives of the study (Kumar 1996 p.138). The author therefore agrees to work reliable with a clear research process that could be repeated if wanted. The objective of the study is in one line with the chosen method and identified research questions are an appropriate mean to get valid results.

Ethical consideration

Before starting the writing process of this thesis, various conversations and discussions about the topic were undertaken with school teachers, students and the commissioning body. A short plan of the thesis was written and introduced to the involved parties. Only upon general approval by the commissioning body and the University of Applied Science Arcada, the author started to write her thesis. The author has read Arcada's guide of scientific writing and adheres to it (Arcada 2014). In summary it is agreed on to not use falsification, fabrication or plagiarism. When conducting this study it is also important to avoid bias. That means that findings for example were hidden deliberately or highlighted disproportionately to their actual existence. The data is collected and analysed in an accurate manner and findings are reported correctly without distorting them Kumar (1996 p.191 ff.).

Results of data collection

In table 4 the results of the data collection are presented. In total ten articles could be retrieved that suit the inclusion criteria. All chosen articles are qualitative studies, except article 6 which combines quantitative and qualitative study design. The methods differ between case study, observation, interview, discussion group, questionnaire, workshop, diary-taking, role-play and combinations of these. The articles are sort in alphabetical order by author and a short summary of the main results from each article is given.

Table 4: Presentation of data collection

Nr.	Author and Year	Participants	Method	Results
1	Alter (2012) ”The growth of institutional deception in the treatment of Alzheimer’s disease: The case study of Sadie Cohen”	one person with Alzheimer’s disease	Case study	Deception is an easy to learn technique which arises naturally, but the danger is that it may become merely a management strategy and habitual used without considering the context.
2	Blum (1994) ”Deceptive practices in managing a family member with Alzheimer’s disease”	34 family caregivers	Observation, Interviews, Follow-up Interviews	Family caregivers learn to use lies within peer support in order to cope and have a bad conscience about violating normal expectations of intimacy and trust.
3	Day et al. (2011) “Do people with dementia find lies and deception in dementia care acceptable?”	older people with memory disorders	Discussion group (n=4), Interviews (n=10)	People with memory disorders found that lies told in the best interest are considered to be acceptable. Acceptibility depends on three factors: the lie itself, the person being lied to and the person telling the lie.
4	Hasselkus (1997) ”Everyday ethics in dementia care: Narratives of crossing the line”	day care staff	Telephone interviews (n=42)	White lies are used to control behaviour and cope with care situations. It is argued that the value of respect weighs higher than autonomy and a lie can uphold respect and dignity.
5	Hertogh et al. (2004) “Truth telling and truthfulness in the care for patients with advanced dementia: an ethnographic study in dutch nursing homes”	135 patients, 4 physicians, 78 nurses, 4 psychologists	Observation, Meetings, conversations, Diaries, Interviews, Discussions	Professional caregivers experience moral conflicts when aiming to fullfil their duty of being truthful. Nurses generally want to tell the truth, but find themselves restricted doing so. As a consequence caregivers experience a tension between moral obligations and care ideal.
6	James et al. (2010) “Lying in dementia care: An example of a culture that deceives in people’s best interest”	nurses, care and social workers, volunteers, psychologists	Questionaire (n=195), Workshop (n=34)	Lies were considered to be more acceptable when used for the best interest. Acceptibility of lies was increased post-workshop and one reason might be that many participants initially did not define some of their practises as lies.
7	Long & Slevin (1999) ”Living with dementia: communiating with an older person and her family”	one person with dementia, her son, daughter and nurse	Roleplay	There are conflicts when it comes to truth-telling in the context of dementia care, and it may not be the truth that distresses, but the way that it is conveyed. Good communication is the foundation of good care.
8	Tuckett (2006) ”Registered nurses’ understanding of truth-telling as practiced in the nursing-home: An australian perspective”	19 residents, 23 personal carers, 15 registered nurses	Discussions, Diaries, Interviews, field notes	Research suggests that truth-telling is not as harmful as it is mostly assumed, but in practise withholding the truth is exercised frequently in order to protect residents or their family members. Caregivers gauge how much truth can be taken and risk miscalculation.
9	Tuckett (2007) ”Stepping across the line: Information sharing, truth telling, and the role of the personal carer in the australian nursing home”	19 residents, 23 personal carers, 15 registered nurses	Discussions, Diaries, Interviews, field notes	Telling lies are a mean to make care home residents happy and to worry less. Personal carers see themselves as protective big cushions with good intention.
10	Tuckett (2012) ”The experience of lying in dementia care: A qualitative study”	7 nurses, 7 care assistants, 4 therapists	Discussions, Diaries, Interviews, field notes	It is distinguished between abusive lies and lies for the best interest. Truth-telling can be inhibited by others and alternatives such as ”dancing around the truth” are necessary.

4.3 Content analysis

Content analysis is a method often used in nursing research and has a long tradition. The aim of analysing content is to produce new insight and knowledge and this is done by systematically breaking text of research down into smaller units. There are two different approaches. Deductive content analysis is based on testing an existing theory whilst inductive approach observes smaller elements separately and combines them into a larger whole. In this thesis inductive analysis is chosen, because there is not much previous knowledge about the phenomenon of lying in dementia care, and the main purpose of this study is to produce new knowledge on this theme (Elo & Kyngäs 2008 p.109). When conducting a content analysis it is important to consider that there is not only one way of doing this process and outcome depends very much on the skills, style, insights and abilities of the investigator. On the other hand this is an excellent approach for sensitive topics such as the one on hand (Elo & Kyngäs 2007 p.113 f.).

Initially every article was read carefully many times. The process continued by grouping the data, which means that categories were generated freely (Elo & Kyngäs 2007 p.111). For the first question every argument that was made either speaking for the use of lies or against the use of lies was marked on every article separately. In order to save printing paper, the marking was done electronically with the computer on the document itself. In order to answer the second research question this process of grouping data was repeated and all factors that contribute to more or less acceptability of lies were marked. This resulted in two large lists of findings. Both were read and re-read carefully to find similarities. The findings of each question were sort into suitable themes. These themes served as headlines and every finding that fell under the theme was sort in as category and sub-categories. Nothing that was marked in the data was left out. If a specific statement did not fit into any theme a new theme was created, or a theme was adapted so that the finding fits in.

5 RESULTS

After collecting and analyzing data, the following two chapters present the results of this process. The chapter 5.1 summarizes the first research question and presents all arguments mentioned in the articles that speak for the use of lies in communication and all that speak against respectively. In chapter 5.2 the second research question is dealt with by pointing out nine factors that influence acceptability of lies in communication.

5.1 Argumentation of lies in dementia care

Table 5 summarizes the most important arguments that were found to either speak pro or contra lying, showing the debate in current research. The question that is dealt with is “How is the appropriateness of lies in daily communication used by caregivers with older people who have memory disorders argued?” For better reading table 5 is a shorter summary of the findings and shows only the most important arguments that were found. The full table can be accessed in Appendix 2. The results are summarized as themes, categories and sub-categories. Every theme got a letter between A and H for further referral. The letters help to connect the table with the following text, in which the results are presented in greater detail.

Table 5: Results to research question Nr. 1 – "How is the appropriateness of lies in daily communication used by caregivers with older people who have memory disorders argued?"

	Themes	Categories	Sub-categories
A	Person-centeredness	A lie can never be person-centered	Interaction must be honest
		A lie can be person-centered	Contextual with good intention for the best of everyone involved
B	Psychological, cognitive and physical well-being of the older person with memory disorders	the lie has various positive effects such as calming, saving another's dignity, decreasing fear and protecting the person from physical harm	the truth is considered e.g to be upsetting, confusing and embarassing
		the truth has various positive effects such as it helps to cope	the lie e.g hinders emotional-based coping and has a negative impact on self-image, a discovered lie produces e.g distress, anger and leads eventually to social isolation
C	Cognitive abilities of the person with memory disorder	Awareness of a lie	less able to detect lies but unforseeable
		Forgetfulness	both lie and truth as possible responses will be forgotten soon due to the memory disorder
		Comprehension	understanding, reasoning and explaining in communication is challenged
D	Personal preferences	truth	most people want to be truthful and want to know the truth
			not everybody wants to know all truth
E	Well-being of the caregiver	the lie helps to cope	it relieves caregiver burden, distress and prevents exhaustion
		the lie produces a bad conscience	
F	Caregiving relationships	trust and intimacy	a lie that gets discovered has negative consequences on trust and intimacy
		social relationships	lies are a feature of everyday life in order to not jeopardize the relationship
G	Care environment	limitations such as time, staffing and truth-telling limitations (professional hierarchy)	the lie minimizes harm and conflict, saves time and improves care compliance
			the lie is a 'poverty of imagination'
H	Professional duties and ethics	Autonomy vs. Protection from harm / Paternalism	the lie reduces autonomy and protects from harm
			the truth upholds autonomy
		Integrity	a professional duty to not use lies
		Respect	the lie devalues
			respect is not always accomplished by truth-telling
		Beneficence and Nonmaleficence	the lie is justified upon therapeutic need, but this principle may thoughtlessly drive over other principles

A. Person-centeredness

For interaction to be truly person-centred, it must be based on the premises of honesty and on the perspective that all persons have unconditional worth regardless their state of mind. The use of lies is treacherous, because it depersonalizes and devalues. Lying is also regarded as controlling, manipulating, abusing and exerting power, which is contrary to a person-centred approach to care. On the other hand a lie can be person-centred, if it is chosen carefully in context and utilised for the best interest of everyone involved.

B. Psychological, cognitive and physical well-being of the older person

Nine out of ten articles reasoned that the truth can be psychologically painful, and that the lie may circumvent that pain. Figure 2 illustrates this finding by showing the amount of factors influencing well-being. The truth is considered to hurt, confuse, scare, upset and distress (acute or long-term resentment); it also causes anguish, depression, agitation, embarrassment, fear and anger. The lie as a favourable response is described to calm, minimize harm and conflict, save another's feelings and it eases anxiety, agitation and fear. From figure 2 it can be seen that the effect of telling the truth is devastating on mental health. With only considering these effects mentioned in the literature it can be suggested that the lie is more forthcoming than telling the truth.

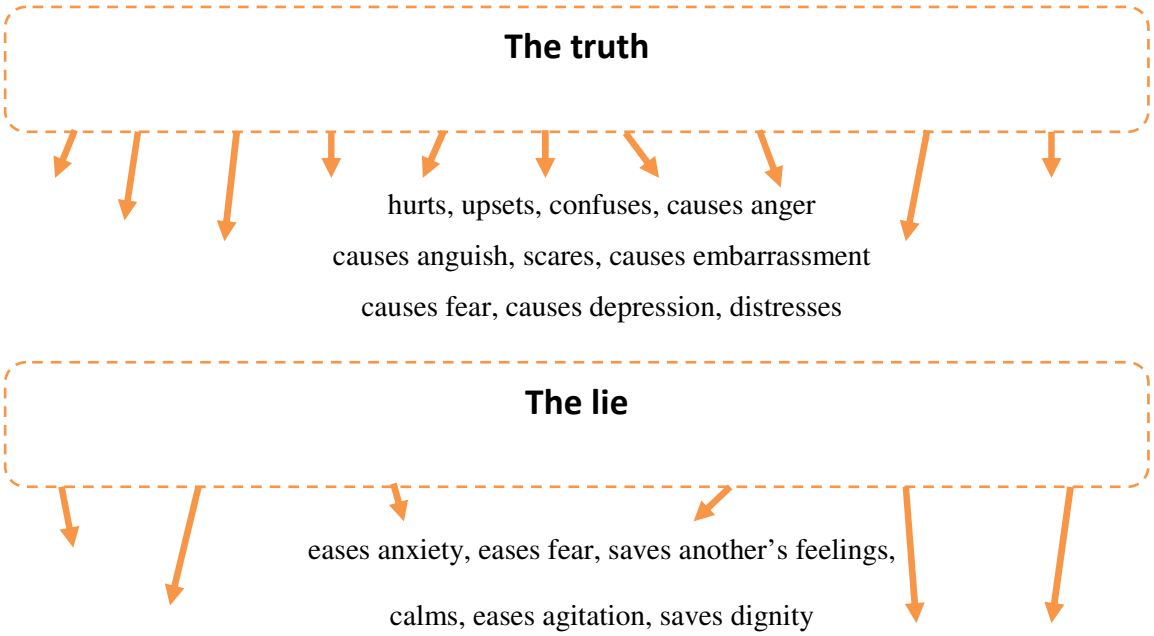

Figure 2: Negative effects of the truth are considered to justify the choice of a lie

On the other hand it might not necessarily be the truth that distresses, but the way that it is conveyed. Also truth disclosure in dementia care may not harm as much as it is speculated and knowing the truth is considered to be less debilitating than worrying about the unknown. For some withholding the truth, because it is assumed that they cannot cope with it is insulting. It is possible that a lie gets discovered and this would produce distress, suspiciousness and anger. Followed by that the person also does not see herself as an ordinary person anymore, but as a person who has a memory disorder. Lying in that sense produces a negative impact on the person's experiences, because the discovered lie reminds of the progressing illness. It was also found that lying may negatively affect memory and exacerbate the dementia process.

People with memory disorders are prone to get into dangerous situation due to their loss of insight and the lie can protect them from harm. In one example described in the literature (2) a family caregiver prevents her husband from the harm of walking off by saying that the doctor ordered he mustn't go out and walk around.

C. Cognitive abilities of the person with memory disorder

It is reasoned that older people with memory disorders are generally less able to detect lies and deception, or that they will forget soon anyway. On the other hand awareness of lies is unforeseeable and the truth that distresses the person with memory disorders will be forgotten soon as well. One of the main reasons why lies are utilized is that reasoning and talking about the truth becomes challenging when the cognitive skills of the person are decreased.

D. Personal preferences

In the articles it is found that most people want to be told the truth, and that most caregivers want to tell the truth. But it is also important to consider that there are exceptions: not everybody prefers to know all truth.

E. Well-being of the caregiver

The lie was found to help coping with the caregiving task, as it relieves caregiver burden and distress and therefore prevents exhaustion. On the other hand having chosen the lie makes the caregiver uncomfortable and guilty about having violated normal expectations of intimacy

and trust in relationships. It is found that the liar's credibility and integrity is damaged and caregivers need to deal with their misgivings, which negatively affects their well-being.

F. Caregiving relationships

Human beings use lies and deception in their everyday life in order to not violate relationships. The motives for telling lies in care situations to older people with cognitive impairment are similar. In clear majority lies described in the research material were told with good intention to enhance well-being of the older person and in order to promote the caregiving relationship. The literature also describes negative consequences on relationships once a lie gets discovered and figure 3 summarizes these. In relationships trust between caregiver and person to care for is fundamental. Lying is a threat to trust and betrays the relationship. Once a lie gets discovered trust is broken, which leads to a feeling of isolation and abandonment on side of the person being cared for. Suspiciousness arises on side of the older person and the valued therapeutic relationship is destroyed. This acts negatively on relationships and on how people with memory disorders view themselves in the context of their social interactions. A lie therefore can support relationships in social accepted norms, but as figure 3 shows it can also betray and act negatively on trust.

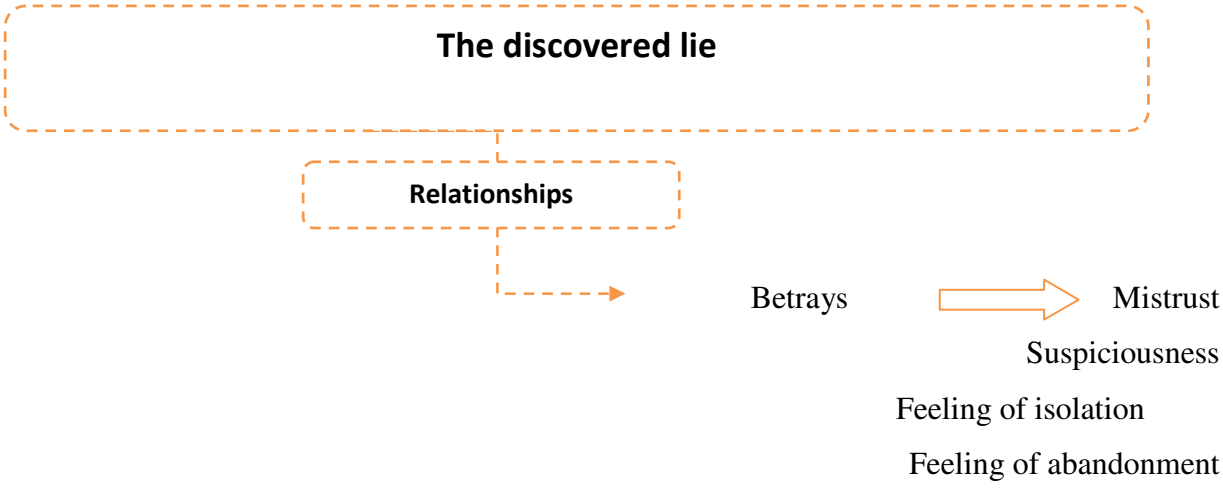

Figure 3: Negative consequences of the lie on caregiving relationships

G. Care environment

There are certain limitations in the care environment that challenge proper communication. The chosen articles mention limited resources such as short staffing, limited support, time, emotional and physical resources, and only few or no alternatives to the lie. Lying as coping strategy can be implemented and learned easily; due to the cognitive impairment it can be

less easily detected and will be forgotten soon. Used to control behavior and to circumvent dangerous behavior, the lie relieves the caregiver burden and distress because it improves care compliance, saves time and energy and the ward work can be kept orderly. The lie therefore works and is essential to cope with the caregiver burden. Contrary to that finding the use of lies is a simple way out in challenging situations and a 'poverty of imagination'. The danger with this communicative strategy is that it may become a commonplace action without regard to situations or persons, contrary to a person-centered approach to care.

Hands-on care staff is working very task-oriented and often not allowed to disclose certain information to their client if a professional with a higher rank or a next of kin asks them not to do so. Their professional role limits their truth-telling abilities and even though there is a desire to be honest it may not be possible in practice. Often they need to pick up routine answers and 'dance around the truth' because they are not obliged to full disclose information. In one case (5) described an elderly man frequently calls for his wife and asks the reasons for being kept in the care home. Only after the psychologists' approval the nurses are allowed to tell him directly the truth: that he cannot leave due to his diagnosis and has to stay there. Only then the situation is resolved, as care workers are allowed to be truthful to him, without the need of deception.

H. Professional duties and ethics

The principle of autonomy means that older people with memory disorders have the right to be informed as pro-active agents and part of the decision making team instead of nonpersons or objects to which the caregivers do things. Allowing autonomous behaviour entails to admit and accept risks and hazards around the person being cared for. Persons with memory disorders get unaware of behavior and likewise limited responsible and upholding autonomy by truth-telling gets into conflict with the duty to protect the persons being cared for from harm. The caregiver is described to act as a big cushion, utilizing lies and deception if necessary in order to fulfil that task. A lie limits the personal possibilities as it exercises power and manipulates choices. In persons with memory disorders though, autonomy is already restricted intrinsically due to the disease and therefore the lie exists in a context of an already violated autonomy. It is argued that paternalism can actually enhance autonomy, as decision making is supported by controlling risks and hazards around the older person. The principle of integrity means that being truthful is a professional duty and intrinsically good,

valuable and respectful. In absolutistic approach of ethics, lies are always wrong. On the other hand apparently strange behavior of the person with memory disorders such as living in the past or denial of deficits have adaptive meaning to cope with the disease and truth-telling can hinder coping. It is the individual perception of the older person's reality that needs to be respected. It is argued that respect is even prior to autonomy and a lie can uphold the person's dignity. In an example chosen from the literature (4) it is described how a client in day care escapes and walks many miles, followed by the caregiver. The caregiver uses a lie whereupon the older person turns around on own choice. The lie was restricting her autonomy as it presented a different kind of reality, but it also enabled the person to choose autonomously to turn around. Her choice was respected and dignity upheld. Alternatively (police) force could have been utilized to bring her back, but this would not be as respectful likewise.

Lies are justified when there is a therapeutic need for the good of the patients and used to enhance well-being. In certain cases caregivers are not duty bound to tell the truth if the end of the act justifies the mean (=Beneficence). Lies are also considered to be appropriate if they avoid harm (=Nonmaleficence). The danger with the principles of beneficence and nonmaleficence is that they may be thoughtlessly chosen, driving over other principles such as autonomy or justice.

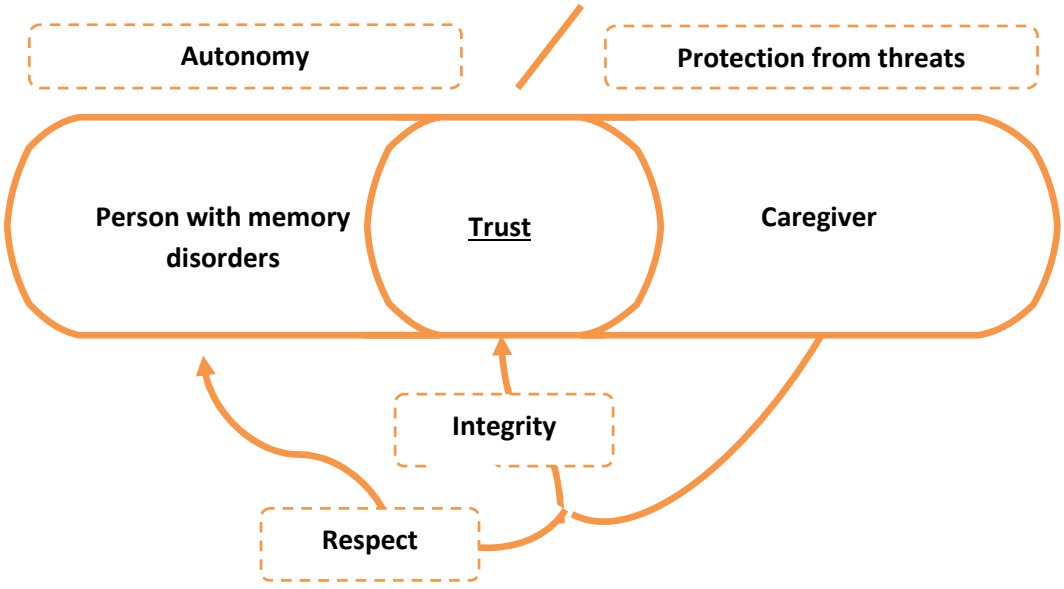

Figure 4: Relationships of professional duties and their interferences

Figure 4 illustrates the relationship of different caregiver duties that may get into conflict with each other. In caring relationships a vulnerable bound of trust exists between caregiver and the person to take care of. The principle of integrity means that the caregiver should act truthful and is a prima facie duty of every caregiver, because being truthful is intrinsically good and supports trust. On the other hand respect may override that principle of being truthful, because the subjective world of the person with memory disorders needs to be respected and this respect is not always fulfilled by truth-telling. The duty of integrity therefore is in conflict with the duty of respecting the older person's subjective world.

Further on allowing autonomy is a very important aspect of caregiving. Being autonomous, such as deciding over one's own life is one determining factor for well-being. Cognitive impairment makes the client group of older people with memory disorders vulnerable for threats which decrease their possibilities to behave autonomously. One of the main tasks of the caregiver is to protect from these threats: On the one hand he or she wants to help the person with memory disorder to behave autonomous, but on the other hand he or she wants to protect the person from harm to his or her well-being. Summarizing the figure 4 it can be noticed that the duty of respect interferes with the duty of integrity and the duty of autonomy interferes with the duty to protect from harm.

5.2 Acceptance of lies in context

When examining the theme of lying in communication with older adults who have memory disorders, it gets apparent that the situational context and the actors involved are crucial for determining appropriateness and inappropriateness respectively. The results for the second research question are summarized in table 6 and respond to "What are the factors that make lies acceptable?" Also for this question results were grouped and summarized into themes, categories and sub-categories. For further referral themes are numbered with letters from A-I.

Table 6: Results to Research question Nr. 2 – "What are the factors that make lies acceptable?"

	Themes	Categories	Sub-categories
A	Awareness	no awareness of the lie	
		awareness	
B	Personal beliefs of care givers and older people with memory disorders	according to context a lie can be acceptable	
		lies are always unacceptable, irresponsive to context	
C	Who is using the lie?	depth and nature of relationships	professional caregivers
			close relatives or friends
D	Intention	good intentions	used with compassion, used to enhance well-being, in order to protect, to for example reduce truth-related distress or aggression
		abusive or manipulative intention	exercising control over the person, improving care compliance
E	Frequency	habitual lying	
		the lie is one option amongst many and chosen carefully	
F	The kind of lie	definition of lies	outright lies
			little white lies
			deception
		responding on which level	fitting into own reality
			creating new reality
G	How is the lie told?	in an individualized, humanizing, respectful manner, holding on personhood	arising from shared dialogue and human relationship
		in a demeaning, devaluing, disrespectful manner	arising from a malignant care culture
H	Alternatives to lies	Variants of truth telling	avoiding the truth, not telling, softening the truth, denial, half-truths, going along, withholding the truth, truth-telling by layers
		others	Validation, transformation, ignoring, carefully telling the truth, distraction, discussing the past
I	Outcome	Who benefits from the lie?	the lie serves in the best interest of the older person with memory disorders
			the lie serves the caregiver or care management only, for example merely as time management strategy
		Does the lie produce harm?	distress, devalue of the person, producing a negative experience of dementia, negative impact on personhood and relationships
		How does the lie effect on trust?	mistrust
			trust is not broken, trust is only temporarily broken

A. Awareness

The lie is described to be more acceptable if no awareness of the lie exists, and less acceptable if awareness is given, because the discovery of a lie has negative effects on well-being (impacting relationships, self-concept and the experience of the disease).

B. Personal beliefs

Acceptability of lies also depends on personal beliefs. For some people lies are always unacceptable, no matter the outcome, no matter the situation they are being used. Some other people believe that lies can be acceptable in a certain context. It is essential to check up with the older person with memory disorders in advance in order to find out how much she wants to know. Besides the beliefs of the person being cared for also caregivers beliefs influence their feelings about using lies and therefore the acceptance of using lies.

C. Who is using the lie?

According acceptability of lies there are differences between the relationships depth. The relationship between the older person with memory disorders and the family caregiver is more intimate; therefore the breach of trust is bigger if a lie gets discovered. The professional caregiving relationship is generally less intimate and expectations are lower: therefore the lie gets somewhat more acceptable.

D. Intention

When lies are used with good intentions in mind, with compassion in order to enhance well-being and in order to protect from harm, injury or to reduce truth-related distress, the lie becomes more acceptable. But when the lie is used in order to abuse or manipulate the person and exercising control over the person, the lie becomes less acceptable. Less acceptable are those lies that aim to get the person to do something, for example lying in order to make someone take important medication. Absolutely inappropriate are the lies that devalue or dehumanize, distress the older person with memory disorder or which produce distrust.

E. Frequency

Within the situational care context lies that are used habitual instead of chosen carefully become less acceptable.

F. The kind of lie

There is no common definition of what constitutes a lie in the context of dementia care. Truth-telling is generally conceptualized as continuum, and exists only in context. Lies categorized as outright lies (telling something very contrary to the truth) were less acceptable than little white lies (small lies with good intention in mind such as misleading a person), because little white lies are very common in any other daily interaction as well. Deception which for example contains withholding the truth is not in itself regarded as lying, but more as a variant of truth-telling and therefore becomes more acceptable. Even people that were speaking strictly against lying emphasized the use of deception as somewhat more acceptable.

There are also differences between lies that fit into the older person's reality and lies that create a new reality. In article 4 a case is described which involved both lies that fit within the same reality of the older person with memory disorders as well as lies that create a new reality.

> This story was about a participant who"decided that the kids needed supervision and she needed to leave the center." The staff member described going after her and using various strategies to get her back to the center:
>
> "I tried approaches like, "The kids are in school, no one's at home right now," and she said, "But I have a key." And then I tried, "You don't have a key, you don't have your purse with you, we have to go back to get your purse." That didn't work. She said, "If I don't have a key, I'll go to my parents' house." I told her her parents were on vacation and they weren't at home; anything that I could keep one step ahead of her. And that din't work. She said, "Well, then I'll bust in a window and crawl through the basement."
>
> Up to this point, the staff member has used minor lies that fit in with the participant's reality, that is, her belief that she was back in an earlier time in her life heading for her parents' house in her home town. After two hours of walking "probably about 4 to 5 miles", the staff member tried a different tactic. She convinced the woman "that there was road construction up ahead and we had to turn around, that we couldn't walk any farther because we were going to be stopped" ...there wasn't really any road construction. (Article 4, p.645)

In the example above the caregiver initially responds on the same level as the person with memory disorder. The older person with memory disorder found herself in a situation that she must have experienced like that many years ago. Even though now she is older and retired and her children are adults, in her experienced reality she wants to take care of her children. The caregiver knows that there are no children the older person can return to, but steps into the story of the older person. She responds on the same level saying that the children must be in school now, and saying that the woman has no keys and no purse. When that strategy does

not help, the care staff decided to utilize a lie that creates a new reality: She says that there are road constructions ahead. Both chosen responses are lies, but the first approach responds to the older person's experienced reality, while the second is a statement wrong to any actual happenings. Lies that respond to the same reality the older person experiences are described to be more acceptable than lies that create a new reality.

G. How the lie is told

Lies that are chosen individually and carefully and told in a respectful manner get more acceptable than random lying without regard to the person and situation. The difference is that lies can arise from a shared dialogue within the human relationship or arise out of a malignant abusing care culture.

H. Alternatives to the lie

Lies become more acceptable when there are no other alternatives available. Variants of truth telling are described to be non-identical with lying itself. Examples here fore are avoiding telling the truth, softening the truth, denial, half-truths or truth-telling by layers. Nurses are found to assess a resident's cognition, mood, and psychological status and gauge whether or not the older person can handle the truth. If the nurse finds that the truth cannot be dealt with, she finds half-truths more acceptable. Other alternatives to lies and withholding the truth mentioned in the chosen articles are transformation, which means that something that has been said is reformulated, avoiding to answer or ignoring, going along with factual incorrect statements or not correcting. Also viable alternatives mentioned is to carefully tell the truth or distract by for example talking about the past or Validation, which aims in responding to the underlying feelings of the words, instead of answering directly on the spoken word.

I. Outcome

In medical thinking, consequences of an action have always been a strong argument about its appropriateness. Beneficence (=to do good) is often a key principle and lies are considered to be more acceptable when they are used for the best interest of the person's involved, and thus the lie is justified by a positive outcome (the end result of the act justifies the means). The golden rule about the acceptability of lies is to not do it yourself either what you don't want to happen to you. When a lie only services the caregiver or management as a time strategy for example, this approach gets less acceptable. A lie also should not be used if it produces harm,

such as a discovered lie would produce distress, having a negative impact of the older person being cared for and her relationships. By telling a lie it should be paid attention to trust of relationship. Trust should never be violated, and if only temporarily.

6 DISCUSSION

The sample sizes of the articles chosen were rather small (between 1 and 195 participants) because the aim was not to generalize the results on the general population, but to understand the phenomena of lying on a deeper level and this is in on line with the aim of this research.

The study participants are representatives of a variety of disciplines (amongst registered nurses, nursing assistants, licensed practical nurses, personal carers, physicians, psychologists, social workers, different kinds of therapists etc.). Their work roles distinguish from each other's, such as people delivering care are the ones dealing with daily challenges in communication. Other study participants such as physicians or psychologists have a different point of view, because they are only indirectly involved in care. They reason the use of lies from a greater distance, as it is mostly the personal carers and the practical nurses who deliver care and who communicate the most with the older person with a memory disorder. This is influencing the results of the studies and needs to be taken into account.

As already mentioned before, the biggest challenge about conducting this review of literature, was that scientific articles of high quality were rare. In the material available on this theme are a lot of highly relevant articles that are backed up with literature but unfortunately lack proper described methods on how they reached their findings, thus they got excluded. The majority of the articles chosen have a clear described research motivation, method, thorough background literature and valid findings, but especially one article is less relevant. (1) is very current, dating from year 2012, but is less well backed-up with literature and uses a case study as method. The results of this article are less relevant for answering the research questions.

Due to a limit of high quality researches, the first research question "How is the appropriateness of lies in daily communication used by caregivers with older people who have memory disorders argued?" is very broad and collects all arguments mentioned in the

research. This led to a huge amount of arguments that are often in exact opposition to each other. It would have led to more insight if for example only the caregivers' arguments pro and contra lying would have been collected, but unfortunately the availability of data was only insufficient. The strength of this work is that it combines a variety of literature sources and can be used to as foundation for further studies.

6.1 The debate about the use of lies

Kitwood's triadic model which was explained in the background can be used to analyse a situation that a lie was utilised:

> A lot of the residents have to leave their much loved pets behind…when they [family] let you know that the dog has died and…resident will say, "Can't wait to see Toby" (laughter) and you know damn well that Toby's dead…It's up to [the family] to tell them. Again "The last I saw of him he was fine." Which is the truth! Because I haven't seen him since the last visit. The fact [is] that I know he's dead (Article 8 p.496)

According to Kitwood's model, the caregiver is an individual with a unique personality, defines the situation in a particular way, has certain expectations, desires and intentions and is in a particular sentient state such as mood, emotion and feelings. She decides to withhold a part of the information, because according to her it is the family who needs to decide whether to disclose the truth about the dogs' death. She also responds cautiously, because she possibly does not intend to hurt the resident with her response. The older woman on the other side has equally an own personality, a particular sentient state and an own definition of the situation. She seems to be happy about her expectation to see her dog in the near future. Upon receiving the answer "the last I saw of him he was fine" the interaction continues, because she starts to reflect on that response. Possibly she thinks that her dog is alright, or sense in the caregivers' response that something happened to him. As this example shows, interaction is very complex and has deep reaching implications.

It is shown that in residential care for people with memory disorders a hierarchy exists which may not allow the caregiver to disclose information full. This is challenging for care workers who know their clients very well, but the final decision about a resident's capacity to cope with the truth rests with the registered nurse as a team leader (8 p.495). There is a clear power distribution in the care sector, and the older person with a memory disorder may not

necessarily benefit from that order, because hands on workers who know the people they care for usually best, are low in decision hierarchy.

6.2 Contextual acceptability of lies

Acceptability of lies varied with certain conditions being met. The initial case that was chosen to illustrate Kitwood's understanding of treachery is going to be revised according to the findings:

> Mrs. D, a childless widow, has no close relatives in the district. Her neighbor reports that she is behaving oddly, and wandering in the street at night. Her nearest relatives, who live some way away, are asked to intervene. They visit her, and tell her that they are going out for a drive, as they have often done. The drive ends up at the geriatric assessment ward of the local mental hospital, and she is admitted. (Kitwood, 1990, p.181 f.)

The lie that was used in this example is an outright lie, which means that someone tells something very contrary to the truth. In that case the intention to drive to a care home was covered by saying that they would go for an ordinary outing. The lie also gets unacceptable for the reason having it utilized in order to make the person doing something. Finally, the lie was told by a nearest relative that tends to make the breach of trust even bigger, as expectations of that kind of relationship are higher than between strangers. In the case on hand it becomes obvious that the lie is inappropriate and unacceptable due to the kind of lie and the relationship of the persons involved.

In the collected data different kind of lies were distinguished as outright lies, little white lies and deception. Further on lies were categorized as those that fit into the older person's reality and those creating a different reality. Background literature also categorizes smaller white lies with good intention and bigger lies that tell something contrary to the truth. In opposite to Vrij (2000) who counts withholding information in order to intentionally mislead other people as a form of lying, the collected data material suggests otherwise. Withholding the truth became more acceptable because it was categorized as a variant of truth-telling. This is incongruent with background literature which suggests that withholding information is a lie of omission.

6.3 Person-centred care and lies

In this work some lies that are told are clearly abusive and not person-centred. The person that tells an outright lie in order to convince an older person with cognitive impairment to move into a care home lacks in empathy and acceptance. The caregiver in that case does not use empathic understanding how it must feel like to live with a memory disorder. Instead of accepting the older person and meeting her on the same level by opening a dialogue about other possible solutions, the caregiver acts from above and decides over her head. The example shows a lack of respect and acceptance of the person, crucial elements for person-centred care. Generally a challenge with regarding a lie as person-centred is the lack of congruence as one of the growth-promoting conditions after Rogers. It requires that the caregiver is real and truly him or herself. According to Rogers (1961 p.33) reality is crucial in any relationship and this means that the caregiver is aware of own feelings and attitudes and able to express them openly. Only by doing so the older person with memory disorder can seek for reality in him or herself. If a caregiver uses lies, he or she sets up a façade and therefore enters a state of incongruence.

Besides congruence also empathy, acceptance and other factors determine whether a lie can be person centred. One of the most important factors of person-centred care is regarded to be a care, that allows the person with memory disorders to continue life as normal as possible (Edvardsson et al. 2010). It is also widely accepted that lies are an essential feature of everyday life (Vrij 2000) and not necessarily abusive (Bender 2007). In that sense lying can be accepted likewise. In one article (3) people with memory disorders have expressed that they want to be regarded as ‘normal’ people and this would include the use of socially accepted lies.

According to Sachweh (2008) the lie that is used in elderly care situations arises by putting own understanding of right and wrong behind and stepping into the experienced reality of the person to take care of. This is a way of feeling with the person and accepting his or her behaviour. The results of the data that was analysed also showed that there are differences between the attitudes of the caregivers using the lie. Empathy is one of the main elements of good quality care and one example from the literature illustrative compares different approaches.

> Mrs. G is a simple working-class woman and mother of a family of 13 children. Her husband was a farm laborer and the family has never been very well off. All her life Mrs. G. has had difficulty in making ends meet. (Article 5)

In the care home she is mostly under the impression to be looking after her children whilst her husband is working. She is extremely attached to her handbag and gets agitated if she loses it or if she notices it to be empty with her purse gone. *"Look, my purse is gone, I have been robbed"* (5) she would report panicky to the nurses. One nurse responded that her money was being kept safe by her children and that she has no reasons to worry. This was the truth, but it did not take her panic and worries, so that eventually tranquillizing medication was given. It can be argued that it was sincere to respond truthfully, but it is doubtful that the worries of Mrs. G. were responded to empathically. In the same case described one of the nurses suggested a different approach to responding truthfully. She suggested handing out a purse with money to Mrs. G so that she can pay if that is what she wants. She explained her suggestion by saying

> You can't go anywhere without money! You must see it from her point of view: she's got to look after 13 children. I'd panic if I was in that situation and didn't have any money (Article 5).

This nurse puts herself into Mrs. G. shoes and imagines the situation from the older person's point of view. Whilst it is a form of deception to give her a purse with money, even though in the care context Mrs. G in fact does not need money and would not actually pay anything for, it is an empathic way of responding to Mrs.G's reality.

As shown a lie can be an empathic way of meeting a person with cognitive impairment by accepting his or her behaviour unconditionally, but after Rogers it is incongruent to set up a façade (1961 p.33, 1967 pp.-90-92).

6.4 Future research recommendations

In the future more research is needed on the perspective of older people with memory disorders themselves, because they are the target group of care. There is already one article on the theme of lying that uses their perspective in research (3) and it is their opinions, wishes, desires and needs which can be used to develop dementia care. Studies that use older people with memory disorders themselves are for example necessary to find the often mentioned "best interest". If caregivers thoughtlessly assign themselves as experts of

someone else's life, it gets necessary to help them empathise with the older person they care for and to use an approach that helps to meet the 'best interest'. In the topic of interest communication always happens between a sender and a receiver, therefore research on the caregiver is necessary as well. As discussed before a lie is not only a lie, because the context is crucial. Studies that research the conditions of care and the threats to proper communication can be used to meet the caregivers' best interest and needs as well.

7 CONCLUSIONS

Generally lies are described to be acceptable when they are used in the best interest of the persons involved. Such are lies that do not distress, devalue or produce distrust, and that are told in an individualized and kind way so that the lie does not impact negatively on personhood. There is no static view about the acceptability of lies, and therefore a unified approach regarding lying and truth-telling is not possible. Largely described, the acceptance of lies depend on the factors of the lie itself, the person being lied to and the person lying. In the chosen literature abusive intention was mentioned only in minority. Most of the caregivers used lies as a way of coping with caregiver burden, out of a need to adhere to a care hierarchy, or out of a desire to make the life of the people taking care of as comfortable as possible. Lies are a feature of everyday life, but in relationships between a caregiver and a person with memory disorder is a huge risk for abusive lies due to the power imbalance. Abusive lies are clearly not person-centred.

While working on this theme, a fine line emerged that splits the use of lies between acceptability and unacceptability, just as lying is acceptable in a certain context between adults without memory disorders or by adults with their children. The theme is highly controversial which results in strong arguments and a discussion partly led on an emotional or spiritual level. But caregivers of older adults with memory disorders are dealing daily with high challenging situations that often contain an ethical dilemma: They need to be guided around this theme and instead of bad conscience for using an approach that has been disapproved it is important to promote a good approach to caregiving instead. The author hopes to present a work that offers insight on this theme.

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9 APPENDICES

Appendix 1

Case examples of lies, deception and withholding the truth

A. The caregiver is confused with somebody else

A care home resident with memory disorder repeatedly confuses a care worker with her neighbor in former times. In the case given the contact benefits her well-being, because she used to have a good relationship with her neighbor the care worker would not correct the misunderstanding and use a lie to respond (Sachweh 2008 p.268). The aim of the lie is to give her pleasure and to avoid distress (Sachweh 2013 p.114) and this is fulfilled by not correcting the residents' assumption.

B. A lie is used to soothe pain and grief

According to Sachweh (2008 p.268) a white lie may be used to explain the present reality which is not understood by the person with memory disorders disoriented to time and place: A care home resident with memory disorder craves every morning for her deceased parents weeping crocodile tears. By responding that her mum is in the kitchen and her dad is already at work, a lie is used to soothe that pain. Another example would be to tell residents with memory disorders who do not understand why they live together with all those old people that they are on vacation or that there are renovations in their flat.

C. The person with a memory disorder fails or makes a mistake

Thirdly care staff is using white lies to distract from actions the older person with memory disorders did not succeed in or did wrong. The aim is to uphold the person's dignity: A male resident tries to shave his face with a Dictaphone and fails. He is frustrated and angry. A young care worker observes this incidence and responds cautiously by responding *"Such an old broken device. Wait a moment I will bring you a functioning sharp razor"* (Sachweh 2008 p.268). That way, the resident will be saved from embarrassment and calmed down by distracting from his anger and frustration about his failure instead of confronting him (Sachweh 2008 p.268).

D. Lying to protect the older person from possible physical harm

A diligent former secretary who left the care home several times and needed to be brought back partly with the help of police force continues to leave the care ward unattended every day. As soon as this attempt is recognized a care worker calls after her *"Mrs. Meier, a phone call!"* (Sachweh 2008 p.270). She quickly turns around and answers the nearest telephone, speaking to a care worker that improvises a phone call, for example asking for her boss or canceling an appointment. In this example the resident can exert her sense of duty and is distracted from her attempt to leave the care ward. Ideally this approach is extended by inviting her for a coffee and talking about the good old times (Sachweh 2008 p.269 f.).

E. An outright lie

The son of an older woman who has a memory disorder convinced his mother to move into a care home by saying this will be only for a short while for one or two days so that she can check out whether she likes this place and get some medical check-ups. She only realizes that this is her new residency after her son carried in several boxes with all her clothes a few days later (Taylor 2009 p.15).

F. Truth-telling and distraction

In this example a variety of approaches are used that help both nurses not to tell lies. Nurse 1 explains rationally on the basis of objective truth *"I'm writing my report now and your daughter is working at the moment."* and changes the topic *("we'll be going to the choirsinging in a moment"*). Nurse 2 intervenes and distracts *("what a lovely dress you've got on"*) this intervention leads to a moment of confusion on side of Mrs. H, whereupon she takes up her inquiry autonomously.

> [Nurse 1: "Oh dear, here she comes again."
>
> Mrs. H: "Could I just ring my daughter; I would like her to come and pick me up now."
>
> Nurse 1: "We'll phone her later on Mrs. H. I'm writing my report now and your daughter is working at the moment. We can't disturb her there. Besides: she knows you're here with us."
>
> Mrs. H: "Oh no, I want her to come at once. She surely will do so, if you would only ask her."
>
> Nurse 1: "But Mrs. H we'll be going to the choir singing in a moment. They are expecting you."

Mrs. H: “But I don’t want to go there. Please, I want to go home. I don’t belong here! You’ve taken away my freedom.”

The nurse was lost for words for a moment and looked at her colleague, who said:

Nurse 2: “I say, Mrs. H, what a lovely dress you’ve got on. And that brooch looks beautiful with it. If I could look as good as you do at your age, I’d be happy!”

Mrs. H: “Do you think so? Well, thank you very much…but…but I wanted to ask you something, what was it again? Do you know?

The nurses did not answer.

Mrs. H: “Oh yes, I remember: I must phone my daughter. She really must come and fect me now. Please, help me, it is so horrible here…” (Article 5 p.1688)

G. Transformation

Here the nurse transforms the original words of the care home resident into a question and therefore avoids answering directly to the request of Mrs. S. She avoids both the lie and telling the truth likewise. The nurse uses transformation to distract the attention from what has been originally asked to another topic.

Mrs. S: “I say miss, could you please give me my coat. I’ve got to go out.”

Nurse: “Oh, you are cold, is that why you’re asking for your coat? Come on, I’ll give you a cardigan and we’ll go and have a cup of tea together. Then you’ll be all nice and warm again.” (Article 5 pp.1687-1688)

Appendix 2

Table 7: The full account of results to research question Nr. 1 – "How is the appropriateness of lies in daily communication used by caregivers with older people who have memory disorders argued?"

Themes	Categories	Sub-categories
Person-centeredness	A lie can never be person-centered	Interaction must be honest, genuine and respectful, the lie depersonalizes, is treacherous, controls, dominates, manipulates, betrays, controls, abuses and exerts power
	A lie can be person-centered	Contextual with good intention for the best of everyone involved
Psychological and cognitive well-being of the older person with memory disorders	Positive effects of the lie	The lie calms, saves another's feelings and dignity, eases anxiety, agitation and fear
	Negative effects of the lie	A discovered lie produces distress, suspiciousness, anger, social isolation and a sense of abandonment
		The lie produces a negative impact on self-image, hinders emotional-based coping, assuming that the truth cannot be coped with is an insult
		Lying effects memory negatively and exacerbates the dementia process
	Positive effects of the truth	The truth helps to cope, is less debilitating than worrying abut the unknown, does not harm as much as often assumed, not the truth itself hurts but the way it is conveyed
	Negative effects of the truth	The truth hurts, confuses, scares and upsets. It causes acute distress and possibly long-term resentment, embarrassment, agitation, depression, fear and anger
Physical well-being of the older person with memory disorders	Positive effects of the lie	It protects in situations danger to safety and circumvents dangerous behavior
Care environment	limitations	limited support, time, emotional and physical resources, short staffing, only few or no alternatives to the lie, truth-telling limitations (professional hierarchy)
	positive effects of the lie	the lie minimizes harm and conflict, saves time, protects valuable items, Improves care compliance and helps to ameliorate disruptive behavior
	negative effects of the lie	the lie is a simple way out in challenging situations, a poverty of imagination, if used habitual
Well-being of the caregiver	Positive effects of the lie	Relieves caregiver burden and distress, helps to cope and prevents exhaustion

cont. Table 8: The full account of results to research question Nr. 1 – "How is the appropriateness of lies in daily communication used by caregivers with older people who have memory disorders argued?"

	Negative effects of the lie	Dealing with misgivings to have violated normal expectations of intimacy and trust. Liar's credibility and integrity is damaged, bad conscience
Caregiving relationships	positive effects of lies	Lies are a feature of everyday life in order to not jeopardize the relationship
	negative effects of lies	Trustworthy relationships are fundamental and lying produces distrust and violates intimacy
Professional duties and ethics	Autonomy	is already restricted due to the cognitive disease, the lie reduces and the truth upholds autonomy, caregivers duty to admit and accept risks and hazards of autonomous behaviors, personal information belongs to persons concerned
	Paternalism	the lie protects from harm and persons being cared for rely on protection, can enhance autonomy
	Integrity	a professional duty to not use lies, truth is valuable and intrinsically good
		truth-telling principle is difficult to uphold in practice
	Trust	truthfulness is fundamental to trust, relationships are build on trust
	Respect	of the individual perception, everybody has unconditional worth and the lie devalues, not always accomplished by truth-telling – face-saving deception
	Absolutist approach	the lie destroys human dignity of the liar, is unethical and always wrong
	Beneficence	consequences of the lie do good, the lie is justified if there is a therapeutic need, above all do good
		may thoughtlessly drive over other principles
	Nonmaleficence	avoiding harm by for example avoiding harmful perceived truth
Cognitive abilities of the person with memory disorders	Awareness of a lie	less able to detect deception, but awareness is unforeseeable
	Forgetfulness	the lie as well as distressing truth will be forgotten soon
	Comprehension	understanding, reasoning and explaining is challenged
Personal preferences		most people want to know the truth
		generally caregivers want to be truthful
		not everybody wants to know all truth