# Communication between healthcare professionals and people with dementia: is deception an act of care?
## Integrated Literature Review

**Joana Cabral da Silva**

Dissertação para obtenção do Grau de Mestre em
**Medicina**
(Mestrado integrado)

Orientador: Prof. Doutora Rosa Marina Lopes Brás Martins Afonso

**Covilhã, abril de 2023**

# Declaração de Integridade

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Joana Cabral

# Dedicatória

Ao que me inspirou em perguntar sobre a importância deste tema. Ao que sabia sempre quando ia a cair, e me segurava com tudo o que tinha para dar. Ao que me explicou, vezes e vezes sem conta, a importância de um gesto de carinho, de uma palavra, de um momento de companhia. Ao que me mostrou o valor numa partilha de memórias, de gargalhadas, de "inside jokes", que podem e poderão sempre coexistir com sermos a nossa melhor versão, em educação, em valores morais. Ao que me ensinou, sem diferenciar, a fazer contas de multiplicar e a preocupar-me e cuidar dos que mais amo. Ao que sempre me lembrou da importância de aparecer, de estar. Ao que me guardou sempre e continua a guardar. Gostava de poder imprimir este documento e mostrar-lhe, para ver a cara de felicidade por mais uma conquista. O olhar emocionado, de orgulho, e de amor quando lhe lesse esta dedicatória, que nunca seria para mais ninguém além dele. Mas, mesmo na falta disso, continua a ser quem me encoraja todos os dias.

Ao meu Anjo da Guarda.

# Agradecimentos

À Professora Doutora Rosa Marina Afonso por toda a paciência, apoio e ensinamentos, por não me deixar esquecer do valor do que tentamos fazer aqui, e ajudar-me a ser um bocadinho melhor no futuro com as pessoas de que estarei rodeada.

À minha mãe, Maria José, por toda a força, pachorra, apoio, orgulho. Farei sempre o meu melhor para tentar corresponder à visão que tens minha que te orgulha, para te agradecer encorajares-me sempre nos meus sonhos, pelas asas que sempre puseste nas minhas costas o melhor que sabias para me deixares voar até onde eu quisesse.

Ao resto da minha família que sempre lutou ao meu lado, sem me deixar baixar braços.

À Inês. Por tudo o que ela sabe, pelas coisas do destino que nem sabemos explicar, pelas palavras que já não chegam e pelos murros emocionais com discursos sempre que preciso deles. A minha âncora que nunca me deixa afundar. Aos B's todos que juntamos na vida, com a mensagem certa, no momento certo.

Ao João. Por acreditar sempre nas minhas capacidades, mesmo quando eu duvido delas. Ao que me lembra sempre que família é também a que vamos criando no caminho; e me faz feliz por ter encontrado nele o irmão que nunca tive.

À Patrícia, por toda a porrada emocional necessária, correção de vírgulas. A madrinha de praxe que fica com os meus apontamentos, que continua sempre a ser a mais velha e um exemplo nas reflexões do quotidiano, que me fazem querer ser no dia de amanhã uma profissional melhor, como sei que ela vai ser.

À minha Luana, por me ajudar sempre a levantar – depois de rir da queda. Por me ajudar sempre a não levar as pequenas coisas tão a sério e a tirar-lhes peso. Pelos esclarecimentos das dúvidas sempre existenciais que são dignas de livro.

Às minhas meninas da Covilhã, Eduarda e Catarina, pelo apoio, noites de karaoke, os meus SNS24 em emergências, as que mais me tiraram risos nos últimos seis anos e que mais me ampararam sempre que precisei, e que sempre me fizeram sentir agradecida por ter escolhido vir aqui parar.

À Covilhã. Onde as ruas têm um bocadinho das minhas gargalhadas, das minhas crises, das minhas quedas tristes de aselha, das minhas queixas a subir. Àquela que, iluminada à noite ao longe dá logo a sensação de estar em casa. Àquela que agora também é um bocadinho minha.

Aos meus Avós, José e Marlene. Por me terem criado como se fosse outra filha, por cuidarem de mim como podiam e sabiam melhor. Sei que muito do que sou hoje é a vocês que devo, e é o meu maior motivo de orgulho. Continuarei a tentar ser a minha melhor versão, com os valores que me deram sempre.

A mim. Pelos muitos percalços no caminho que se vão tornando visões distantes. Por estas pessoas de coração que tive a sorte de conseguir ir juntando pelo caminho. Para me continuar a lembrar que quero dar de volta todo o carinho e dedicação que deles recebo. Haverá sempre muito a crescer e a ser feito. Prometo não parar de tentar.

# Resumo Alargado em Português

**Introdução:** Entre os grandes avanços tecnológicos que temos vivenciado nas últimas décadas, e o consequente investimento nos cuidados de saúde, a população está a alcançar idades mais avançadas de vida. Assim, há muitas doenças crónicas a ganhar relevo, comprometendo a qualidade de vida nestas idades.

A demência, como um todo, é uma das principais responsáveis, uma vez que engloba uma deterioração cognitiva que se observa em diferentes domínios, e que se reflete em problemas a nível da memória a curto prazo, personalidade, comportamento e, consequentemente, um comprometimento da capacidade de comunicação destes indivíduos. Tal leva a uma crescente exigência no número de recursos, na quantidade de atenção médica, e, consequentemente, na necessidade de se estabelecer uma melhor conexão entre pacientes e profissionais de saúde, que permita uma comunicação mais eficaz. Entender as suas necessidades, as suas dores, é um desafio para o qual os nossos serviços de saúde não estão ainda preparados. Como tal, é um assunto a necessitar de mais atenção social, merecendo a pena analisar o que tem sido feito.

É aqui que se introduzem os conceitos de deceção e mentira terapêutica.

A existência das Pessoas com Demência no seu próprio plano de realidade leva à necessidade de outras ferramentas de aceitação da sua realidade. A aceitação da deceção e mentira não é isenta de críticas, abrindo portas a importantes discussões sobre o que é moralmente correto, sobre o que pode ser uma aceitação do Paternalismo médico, e sobre o que são verdadeiramente cuidados centrados no paciente.

Com este estudo pretendemos, primeiramente, sistematizar os estudos existentes que abordam o conceito de deceção e mentira terapêutica em Pessoas Com Demência, quando praticada por profissionais de saúde. Esta sistematização foca-se na avaliação dos pensamentos de Pessoas Com Demência e dos seus cuidadores no assunto, bem como na avaliação destes nos profissionais de saúde, identificando as suas razões e motivos de relutância para admitir a prática da mentira.

**Metodologia:** Trata-se de uma revisão integrada de literatura sobre estudos publicados desde 01/09/2011 até 01/10/2022, sobre deceção em Pessoas Com Demência. Foram consultadas as bases de dados Pubmed, Scopus, Web of Science e Scielo, tendo sido incluídos os estudos que cumprissem os seguintes critérios: estudos em Português, Inglês ou Espanhol, com o texto completo disponível, centrados em pessoas com demência de qualquer etiologia, onde o conceito de mentira associado a deceção estivesse mencionado em conexão com o papel dos profissionais de saúde.

**Resultados:** Os estudos analisados sugerem que o processo da deceção - sobretudo a mentira terapêutica - não é bem visto entre profissionais de saúde devido às suas implicações morais e legais; mas revela ser bastante comum nas instituições de cuidados a pessoas com demência. Houve, ao longo dos anos, a sugestão de algumas linhas de orientação, mas estas não obtiveram a atenção necessária, também por falta de apoio legal e de comunicação com as pessoas implicadas. Observa-se que há alguns a considerar algo tolerável, olhando para o processo como cuidados centrados no paciente.

**Discussão:** Os resultados revelam ser necessária uma discussão aberta sobre os termos de "deceção" e "mentira terapêutica" quando aplicados a pessoas com demência e às suas respetivas particularidades. O *tabu* à volta destes termos tem de ser reconhecido. Mais que a definição moral destes termos, são precisas algumas orientações legais, para proteger os intervenientes, e garantir que as pessoas com demência têm o respeito e dignidade que precisam e merecem nas suas situações atuais em específico.

A conexão que os profissionais de saúde estabelecem com as Pessoas Com Demência, a intenção com que praticam um ato decetivo, o foco que têm em mente quando o fazem, são tudo fatores que têm implicações quando tal se torna necessário. A mitigação do stress em Pessoas Com Demência, a validação destas numa conversa, por escuta ativa, permitindo-lhes manter a sua dignidade como interlocutores profícuos, possibilita a sua existência no fim de vida com maior qualidade de vida, mais bem-estar, e com melhores ligações estabelecidas com os cuidadores formais que as rodeiam.

# Palavras-chave

Demência, cuidados na demência, deceção, profissionais de saúde, comunicação.

# Abstract

**Introduction:** With the great development and consequent investment on healthcare we've witnessed in the last decades, there are many chronic diseases gaining relevance, compromising the quality of life in older ages. Dementia is one of the responsible for this; demanding more resources, more medical attention and, consequently, the need to have good communication between health practitioners and patients. Their memory issues and compromised communication capabilities are translated in many behaviour changes. Understanding their needs is a challenge healthcare is currently not ready to satisfy, making it a subject in need of more attention in our society, and therefore worth of analysing what is currently being done.

**Methods:** This integrated literature review analyses studies published from 01/09/2011 to 01/10/2022 focused on the application of deception in PWD, done by healthcare professionals. The Pubmed, Scopus, Web of Science and Scielo databases were consulted, and studies that met the defined inclusion criteria were included: studies in Portuguese, English or Spanish; with full text available; clearly targeting PWD of any aetiology, where the concept of lying associated to deception was mentioned, connected with the healthcare professionals' role.

**Results:** The analysed studies suggest that the process of deception, especially the therapeutic lying, is not well seen between healthcare professionals due to the moral and legal implications, but that it's rather common throughout the facilities caring for PWD. There have been some guidelines suggested over the years, but they didn't gather the necessary attention, as there is no legal support, nor enough rapport from the implied PWD as well. It's seen how it's considered condonable when looking at the situation from a patient-centred care point of view.

**Discussion:** Given these results, there must be an open discussion about the terms of "deception" and "therapeutic lying" in their application of PWD and their particularities. The taboo around these terms has also to be addressed. More than the moral definition of these words, it's also needed some legal guidelines, to protect both sides, and ensure PWD have the respect and dignity they need and deserve in their own specific current situation, by validating them, establishing meaningful relationships with them, where they don't feel inferior, increasing their quality of life.

# Keywords

Dementia, dementia care, deception, healthcare professionals, communication.

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| | |
|---|---|
| PWD | People With Dementia |
| AD | Alzheimer's Disease |
| WHO | World Health Organization |

# Introduction and contextualization

"You have a dementia."

It's such a powerful word these days, in many families, in many households.

The shift we've been able to witness in demography, in the form of the population aging, leads to a growth in the prevalence of People with Dementia (PWD), as it's usually associated with the older adults community, not only establishing an increased global burden of disease associated to dementia, but also creating the need of governmental, healthcare, and social-care responses (1,2).

Dementia presents in different forms. We can categorize it, in a vastly simple way, as "neurodegenerative" and "non-neurodegenerative" (3). The dementia presented in older ages usually runs with neurodegeneration (3). Although Alzheimer's Disease (AD) is the most frequent one, there are many presentations of dementia, such as Lewy bodies dementia, vascular dementia, frontotemporal dementia, Parkinson's disease, between others (2,3). Since these pathologies form a vast group, the word "dementia" is commonly used representing chronic, progressive brain diseases, in which we can find issues related with the loss of cognitive function. This organic deterioration can be observed in six bigger domains - executive ability, learning and memory, complex attention, language, social cognition and perceptual–motor–visual perception, causing changes, for example, in short-term memory, personality, behaviour and communication (1,2,4,5).

These set of possible symptoms and their consequent varied combination, allied to the multifactorial causes of dementia, creates a challenge for health professionals to do an accurate diagnosis of the one in question: the disease presentation can be variable, and even overlap the signs and symptoms of other diseases (6). A good clinical history is vital to establish a diagnosis, but complementary diagnostic tests can be a powerful aid in those cases (7). The fact that we're talking about mostly senior citizens implicates increased difficulty in the diagnosis, as there usually are more issues not only in the recognition of the symptoms themselves, but as in its expression and consequent management, leading to the delay of a formal diagnosis and bigger loss of quality of life (2).

The World Health Organization (WHO) classifies dementia in three stages: mild (early stage), moderate (middle stage) and severe (late stage). There's a growing cognitive impairment, reflected in the severity of the signs and symptoms the person presents with. While it can go easily unnoticed on the early stage, it becomes evident in the middle stage, with the difficulties communicating with the people around them, confusion, and repeated questions (1). Language is usually the first affected cognitive field, and we need to consider its nonverbal dimension as well (the tone, the pace, the hand gestures while talking…) as it brings heightened difficulty in the expression of feelings, symptoms, pain (8). Patients with severe dementia are, most of the time, unaware of their location, of the time, may become aggressive and have many troubles recognizing family and friends (1). It's also the stage where affective symptoms become more frequent, needing special attention, treatment, and coping mechanisms (9).

In such a fast world, we still didn't find a way to accommodate the needs of the people suffering from these diseases, which is not only problematic in logistics, but especially in ethical terms (10,11). It raises questions on how to keep the humanity of PWD secure when we, as a community, can't get through them, leaving us on an uncertain field of how we can guarantee the best quality of life possible for them (8).

While it cannot answer to every single moral dilemma, the four prima facie principles (Beneficence, Non-Maleficence, Respect for Autonomy and Justice) offer a straightforward and common structure to medical ethics, allowing healthcare professionals all over the world to build proper moral responses in the daily predicaments they find themselves in (12,13).

It's hard to draw the lines when doctors find themselves, many times, facing situations where the Principle of Autonomy, of informing the patient to let them choose, is directly against the Principle of Beneficence, of keeping their wellbeing by sparing them the painful details of their condition, keeping them from distress (14,15). Trying to appeal to PWD when we no longer understand their world can be a challenge (16).

This is where the concepts of lying and deception gain relevance. Morally frowned upon, the act of deceiving is often used between the healthcare professionals when caring for PWD, but apparently not very acknowledged in some positions (16). There's clearly a gap to consider between the theory and the practical work in this dimension, as the clinical outcome may not coincide with the principle itself (17).

One of the main worries about deceiving people lies on the intent of protecting the system, the health institution itself. This brings a negative connotation to something that is quite common in the human life, bringing a new barrier to its fair, open discussion (18). Actually, deception can be used to protect the patients themselves, as it positively affects expectations and possibly generates a placebo effect (19).

Our society is moving further away of the old polarisation of truth being good and lie being bad. Blum defined, back in 1994, four big categories of deception: "Going along", "not telling", "little white lies", and "tricks" (20). However, in 2010 Elvish suggests a model of hierarchical acceptability, based on the assessment of attitudes towards deception, to become the process easier, more reliable, and valid to everyone (21).

There are many instances where lies are, at this moment, considered acceptable, even though it's still a controversial topic. Clinicians start to drift away from an absolute, generic, standpoint, and look at deception as a person-centred approach. Several authors, like Wheaton *et all*, are making clear the necessity found in a revision of the Code of Ethics of the different healthcare professional groups (21–23).

People with moderate to severe dementia live, many times, in their own detached reality (24). In Feil's findings, one of the conclusions is related to the reality orientation being completely unrealistic to PWD, as they're entering a life stage where one of their main concerns focuses on resolution (25). This implies, for Feil, that the acknowledgment of their reality doesn't represent a lie: the empathy of understanding their feelings and what they're trying to resolve inside themselves brings only relief of those feelings, ultimately respecting them in the process and bringing focus to the definition and importance of validation therapy (24,25).

It can be questioned that, if by telling the truth we're doing the right thing, as the truth is owned to everyone else no matter what, or if on the other hand we're bringing them suffering, by trying to detach them from their own, new, reality (26).

Deception is not only found in the form of lies, bringing awareness to the concept of lying. If the caregiver – informal or professional – is just following the wrong belief the PWD already has can be a part of deceptive practices, but not necessarily a lie. Examples of going along with their reality and beliefs can be false promises to calm them down, or even affection items that take them back to their previous lives, in an attempt to ground these people (26).

Many techniques being applied consist of the application of fake stores, fake bus stops, fake nurseries with dolls in the surroundings of the living facilities where PWD reside (27,28). It's a way to protect them, to avoid wandering and possibly getting lost, a way for them to feel independent, connected to their memories, but still overseen by the professional caregivers. Studies suggest to have a positive impact, lowering their levels of distress and agitation, and avoiding the apathy always associated with severe cases of dementia(3,28,29). It's argued they contribute to PWD's wellbeing, respecting the Principle of Benevolence. Despite this, it always raises the question of the lack of truthfulness in their interaction (26,28,29).

Various authors, and the own professionals and family caregivers take into account two big pillars related to the statement of falsehoods: intention and each patient's ability to take that falsehood into a permanent belief. In both cases, it's affirmed it is compassion that motivates this behaviour: the actual truth will bring PWD more anguish as it doesn't follow their newfound reality. It's also referred how it's something done in the best interests of the patient (27,30,31).

It can be argued that if the intention is not to make the PWD believe the actual statement, the falsehood is not necessarily a lie. If the PWD is already on a severe state of the disease and will likely not retain the argument as a belief or a memory, the deceptive argument will only bring emotional content. There won't be no permanent, real belief being formed, avoiding its categorization as a lie. Of course, it's a scenario dependent of the complex notion of what lying is, but the notion that is a lost process in serious dementia cases is more unanimous (29–31).

Others reject compassion as the main intention, mentioning how it can be seen as easier from a management point of view, completely disregarding the patient's remaining autonomy and their own dignity. If the PWD's emotions aren't correctly interpreted, it will only bring more confusion. On the chance of these patients understanding they're being deceived by the ones closest to them, it will only break their trust in the formal and informal caregivers taking care of them. They see it as a disregard for the person in question, a violation of their rights, as well as an open door to keep breeding the concept of paternalism in healthcare (27,29,31). To try to solve this ethical and moral issue, some are proposing a list of factors where deception could be condoned, following a certain hierarchy of priorities, where the first would be always the patient's safety (29,31).

Based on this, the goals for this study, that consists of an integrated literature review, are to:

1) Systematize the existent studies on the concept of deception and lying practiced by healthcare towards PWD; through the thoughts assessment of PWD and their

caregivers, as well as those of healthcare professionals and the identification of the reasons and reluctance of healthcare professionals on admitting the process of lying.

2) Reflect on the next needed steps to correctly normalize this type of interaction with PWD.

# Methods

This study's chosen method was an integrated literature review; aiming to collect, summarise and organize information related to a specific subject, to bring more awareness and comprehension to it, with applicability to the medical practice (32). This integrated literature review work focused on the analysis and systematization of studies published since **September 1st, 2011 until October 1st, 2022**. In order to research more thoroughly about the current considerations on lying to people with dementia, four databases were consulted: PubMed, Scopus, Web of Science and Scielo.

The implemented search term consisted of: ("Dementia" OR "dementia care") AND ("lie" OR "deception" OR "lying" OR "deceptive" OR "lies" OR "truth telling") AND ("communication" OR "care"). This was applied through the four databases cited, in English language, as presented, with the same search outline in each.

The included literature consisted of studies published starting on 2011; written in English, Portuguese, or Spanish language, with full text available. These had to fill in the inclusion criteria defined as investigations where: (I) the target of communication had to be directly on patients suffering from a dementia of any aetiology; (II) there was a clear connection with healthcare professionals and (III) it was mentioned the concept of lying.

As it can be observed in the flowchart introduced in Figure 1., **656 articles** were found in the electronic research. Through the reading of their abstract, it was applied the inclusion criteria described in the previous paragraph; allowing us to remove 252 articles. Other 129 articles were removed by repetition. Out of the remaining pool of 275 articles; 57 were removed for being concluded that they were either reviews, letters to the editor, systematic reviews, or study protocols. After this step, two investigators focused on reading more thoroughly the 218 articles left and check if they entered the scopola of the intended investigation. 196 were excluded as they didn't directly assess the behaviour of lying/deception; weren't directly applied on PWD, didn't focus on the caregiving process or because they didn't focus primarily on healthcare professionals.

Despite the efforts done to reach out to 10 of these articles' authors, as they revealed to be only brief summaries, no answer or access was gathered, leaving us with 11 studies, that became the target of analysis of this integrated review.

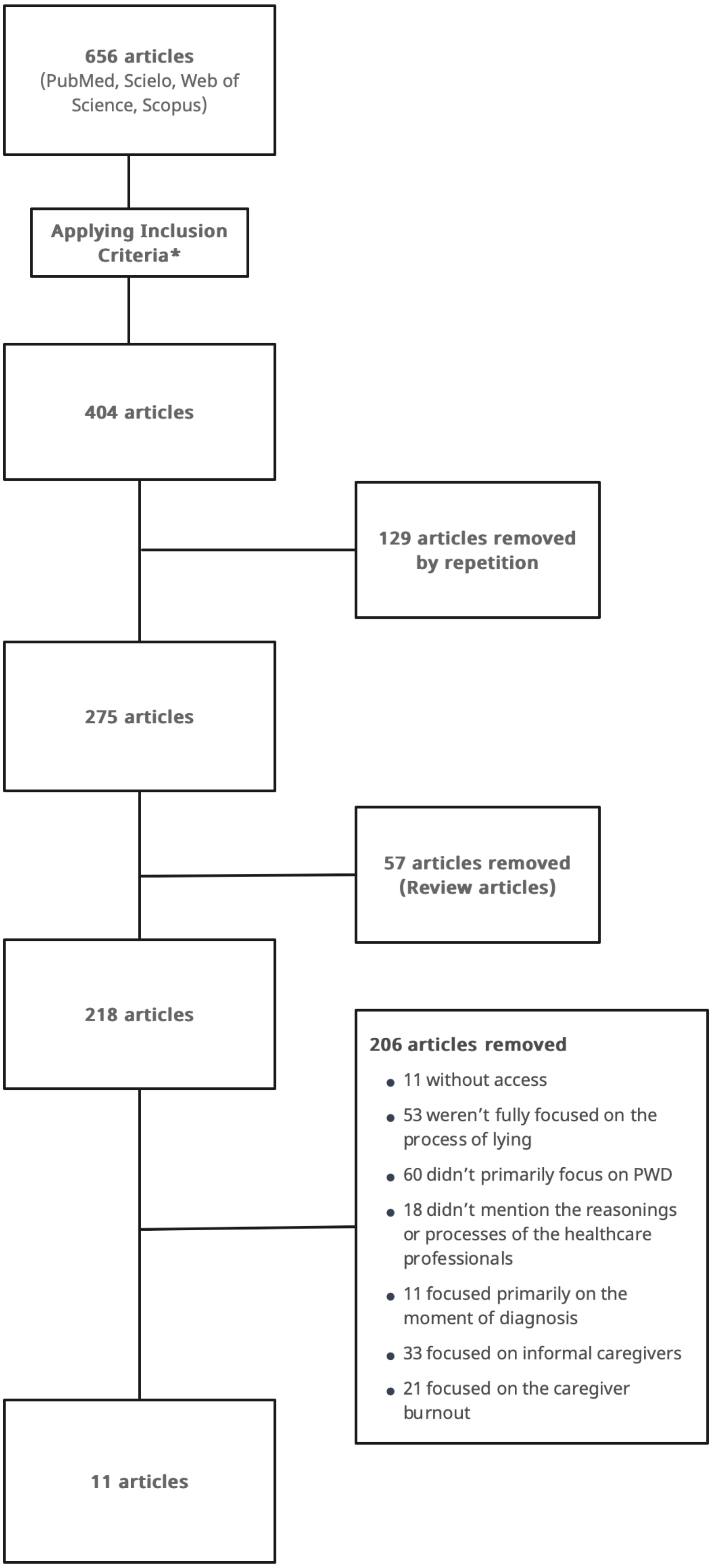

Figure 1: Review study flowchart.

# Results

Between the eleven chosen articles, we can divide them according to their study methodologies:

- 5 Qualitative study (33–37)
- 3 Case study (38–40)
- 2 Ethnographic study (41,42)
- 1 Cross-sectional epidemiological study (43)

These will be shown in the next tables. Although one of the studies also focused on the informal caregivers, we used the information collected between PWD with early dementia towards healthcare professionals (36).

# Qualitative studies

In the following table, it's shown the five qualitative studies. Most of them are focused on nurses and other medical staff in more direct contact with the PWD, but there's two exceptions: one studies and asserts the practices and thoughts of psychiatrists in the area (35); and a more recent study refreshingly focuses on the views of memory impaired PWD that can still give many of their insight on the subject (36).

Something in common in these five articles is the evident need of discussion of the topic, but in an interdisciplinary manner, where healthcare professionals in many areas have an opportunity to discuss the specific case of one PWD with their informal caregivers and the PWD themselves, as the main objective is to always focus the care on the patient, their beliefs, and the trust they want to maintain with them.

Table 1: Selected Qualitative studies.

| **Study** | **Author / Year** | **Objective** | **Study subject** | **Main Conclusions** |
|---|---|---|---|---|
| **The use of the truth and deception in dementia care amongst general hospital staff** (33) | Turner, Eccles, Keady, Simpson, Elvish<br>(2017) | How does hospital staff see their experience with PWD, and which is their thought process deciding whether to tell the truth or opt for deception? | Nursing staff and medical auxiliaries | • Four types of responses:<br>1) Truth telling,<br>2) Lying,<br>3) Distraction,<br>4) “Passing the buck”, leaving the responsibility to answer the PWD to the following attending staff member.<br>• Three main triggering moments:<br>1) Difficult questions (deceased relatives)<br>2) Management of conflicting behaviours<br>3) Share of personal medical information<br>• Reluctance in admitting the act of lying,<br>• Better results / less shame associated when there’s a clearer code of ethics to be applied,<br>• Lack of Communication and Guidance - the topic of lying is seen as a taboo between the professionals, because of the shame it still holds,<br>• Role and responsibility - they consider not know enough of the PWD to lie, or to not have enough trust from them,<br>• Nurses – prefer lying, as it’s quicker and has more chances of success,<br>• Rest of the staff – divided between truth telling or passing the buck<br>• Different ethical frameworks followed, but all in the name of the patient’s best interests:<br>○ Nurses – follow the 4 main principals of Bioethics.<br>○ Other medical staff – Follow their own personal principles. |

| Study | Author / Year | Objective | Study subject | Main Conclusions |
|---|---|---|---|---|
| | | | | • Responses and definitions of lying:<br>  ○ Concept of "passing the buck" – not existent in other studies,<br>  ○ Differences related to the defined hierarchical staff structure,<br>  ○ Synonyms to the word "lie" to take away the emotional and moral weight of it,<br>  ○ Adapting desired response – the response is different depending on who is present around them. |
| **The experience of lying in dementia care: A qualitative study** (34) | Tuckett<br>(2012) | How is the caregiver interaction with the residents with dementia and what is their experience of lying? | Care providers in a residential aged care directly lying to PWD | • Need of more guidance, through an ethical framework that considers theories of good (consequentialism/utilitarianism), of right (Deontology), and of virtue as a precedent to the guidance.<br>• Four-stage communication strategy, where lying is a suitable strategy, but not in the 1st line of action.<br>• Deception seen as an option, and not necessarily a norm to follow.<br>• Importance in educating on the problems of lying and in exploring other strategies.<br>• Importance in staff supervision to avoid making deception the main strategy instead of a focused patient centered care.<br>• Issues with the loss of trust of PWD, as some still retain awareness: lying is something that must be considered and justified as the better approach.<br>• Suggestions related to a consistent care plan (everyone tells the same lie), with documented reasonings to choosing this approach over the alternatives. |
| **Therapeutic Lying in dementia Care**(35) | Culley, Barber, Hope, James<br>(2013) | Obtain the psychiatrists opinion and point of view on the usage of lies, | Psychiatrists from Northeast England | • 69% admits to lying.<br>• 60% condone the use of lies between PWD and caregivers.<br>• The guidelines were considered clear, not needing any improvement. |

| Study | Author / Year | Objective | Study subject | Main Conclusions |
|---|---|---|---|---|
| | | through a non-official 12 item set guideline about lying | | • Only 50% considers ethical to follow the proposed guidelines.<br>• 75% believe they are useful in improving communication skills.<br>• Conflict in the answers – some draw a very definitive line between the omission of truth, and the blatant lie that sometimes is practiced and suggested in these guidelines.<br>• Division of opinions about sharing consent to lie with PWD's family.<br>• Differences in the results against the original study, as this focused only on psychiatrists.<br>• Avoidance of the formal confession to lying as there's only disapprovals on the regulators of clinical practice, discouraging the professionals of using it under risk of legal implications.<br>• The lie is apparently better accepted when not done by healthcare professionals.<br>• Negative opinions are worried with the ethical and practical issues, especially in the bureaucratic part of it, and the difficulty in reaching an agreement on the lie itself |
| **Telling a 'good or white lie': The views of people living with dementia and their carers** (36) | Casey, Lynch, Murphy, Cooney, Gannon, Houghton, Hunter, Jordan, Smyth, Felzman, Meskell<br>(2020) | Explore the experience and point of view of people with memory problems still living in the community | Informal caregivers and memory impaired PWD | • The ones that do not agree with lying at all are focused on their personal values and beliefs.<br>• Throughout the interview, their acceptability increased, admitting value in situations of preventing truth related distress in the PWD.<br>• It's more acceptable to them when the lie is "not telling the whole truth", in the forms of distraction or avoiding.<br>• Importance in considering the level of awareness in the PWD: it's not acceptable to them if the person knows they're being lied to. Therefore, lying was never found acceptable in cases of early dementia.<br>• Respectful lying – in the end, they relate to the PWD individuality and dignity being respected. They consider important to discuss with the families, to know the PWD personal stance on it since they know the PWD better. |

| Study | Author / Year | Objective | Study subject | Main Conclusions |
|---|---|---|---|---|
| | | | | • Fear of representing another way of loss of autonomy for the PWD.<br>• 2 big pillars identified: intention behind the lie, and the impact it'll have on the PWD.<br>• Mentions of needing more information and guidelines in the area.<br>• Concept of *otherism* – the healthy person distancing themselves from PWD in later stages when giving their opinion. It can be a form of discrimination.<br>• The deception should be based on knowledge of the person. It's accepted if they want to do good, and if they know the family's views as well.<br>• All agree that even healthcare needs more interpersonal communication to truly know the patient's needs. |
| **Meaning and practices of spiritual care for older people with dementia: experiences of nurses and care workers** (37) | Hirakawa, Yajima, Chiang, Aoyama,<br>(2019) | Investigate the meaning and practices of healthcare towards PWD | Nurses and care workers caring for PWD | • 3 themes to consider when interacting with PWD: self-esteem, communication, and individual difference.<br>• One approach may not be ideal for two patients, hence trying different actions.<br>• Active listening to help keeping their self-confidence and feel like they didn't lose their value.<br>• Importance of care planning, where the PWD, family members, and healthcare providers should be in contact to understand and respect their social values.<br>• Therapeutic lies found beneficial, through eliminating harm, controlling behaviour disorders, and reassuring PWD.<br>• Need of multidisciplinary teamwork in finding the best approach to each PWD, at least composed of a neurologist, physician, nurse, social worker, and care worker, as a personalized approach is the way to go with these patients. |

# Case Studies

In table 2, we can find the three analyzed case studies.

It can be argued that these do not represent a big portion of the population living with dementia, but these studies give thorough glimpses to PWD's life, humanizing them. They also mention important details that are harder to remember, considering the safety of those around these patients, and the attempt that can be done to connect with PWD even with no guidelines and studies, based on the relationship with them.

Table 2: Selected Case Studies.

| **Study** | **Author / Year** | **Objective** | **Study subject** | **Main Conclusions** |
|---|---|---|---|---|
| **Therapeutic lying to assist people with dementia in maintaining medication adherence** (40) | Mitchell<br>(2014) | Analysis of therapeutic lying applied specifically to adherence to medication | Aggressive AD's patient when not medicated | • Binomial of truth telling / personal and other's safety.<br>• Veracity vs Beneficence – in this case, a lie, not even legal, would have to be told 4 times a day, but it would guarantee his and others wellbeing.<br>• Lack of guidelines – professional or legal – and difficulty implementing any, as battling the discrimination in healthcare is an hot topic, more than ever.<br>• The lying itself keeps happening, with all the legal, ethical, and clinical issues around it. |
| **Parallel Realities: The Interactional Management of Confabulation in Dementia Care Encounters** (39) | Lindholm<br>(2015) | Analyze the responses to a PWD confabulating at a daycare center | Nurses, nurse students and daycare center volunteers | • Two big types of response, at the opposite ends of a spectrum of possible answers to confabulation: evasive response (noncommitment) and concurrent response (acquiescence).<br>• It was found rare to have interactions in the ends of these spectrum.<br>• Open challenge – if the PWD is challenged in his conversation, they're being treated as full participant. It was not very observed, meaning PWD are frequently treated as having less competences in a conversation.<br>• Ancillary questions - allow the PWD to exit the confabulation, and talk about other things, without engaging in the contents of said confabulation, allowing to drift away from the subject and keeping the PWD part of the conversation with the feeling of knowledge.<br>• Acquiescent questions are less frequent, as they actively contribute to the development of the confabulation.<br>• Nurses - more comfortable identifying the PWD's confabulations and answering them noncommittally. It's important since confabulations are showed to be part of a compensation strategy done by impaired PWD's to be able to participate actively in a talk. |

| **Study** | **Author / Year** | **Objective** | **Study subject** | **Main Conclusions** |
|---|---|---|---|---|
| | | | | • Student nurses – More distinct reactions, entering the confabulation and consequently, the PWD's reality - the less knowledge in dementia, more the people elaborate answers, and don't let the PWD built their message. |
| **The Growth of Institutional Deception in the Treatment of Alzheimer's Disease: the case study of Sadie Cohen** (38) | Alter<br>(2012) | Investigate the memory loss of a PWD inserted in a context of real life | AD's patient in a retirement center | • It's not about the technique, but the quality of the relationship, how much of a honest connection is worth<br>• Concept of validation therapy, without being taught, and without challenging the PWD - innate ways to connect to PWD (through direct eye contact, not arguing against the things PWD say with no sense, just answering instead to their level of concern)<br>• It's also discussed how the means of communication must be adapted.<br>• Validation therapy is quite well documented, constituting a good framework to implement in PWD as well.<br>• It's not about to revert PWD to our reality, or to lie with no limits, instead it's about to grab the feelings expressed in the PWD sentences and communicate through it, making them feel loved, needed, and above all, understood.<br>• We can validate even anger, by asking things about what they're feeling but avoiding the "why". it makes them communicate with us, about their feelings, and avert the "crisis". |

# Ethnographic Studies

The two ethnographic studies found bring awareness to an important part in the discussion of deception in PWD: the meaning words can have. While one mentions that lying is a form of a restraint, the other defends that, instead of talking about lying, it can be mentioned as validation; and both can coexist.

This perception of the sense of the vocabulary we use will directly affect as we choose to look at the daily challenges we face caring for PWD, and opens another door to discuss the positive or negative connotation we give to words.

Table 3: Selected Ethnographic Studies.

| Study | Author / Year | Objective | Study subject | Main Conclusions |
|---|---|---|---|---|
| **Informal use of restraint in nursing homes: A threat to human rights or necessary care to preserve residents' dignity?** (41) | Oye, Jacobsen<br>(2020) | Identify the kinds of informal restraints and check how they're applied in healthcare | Nursing homes in West Norway | • 5 types of informal restraint (due to location, architecture, and institutional collectivist constraints in relation to care work):<br>○ diversion of residents' attention.<br>○ white lies.<br>○ persuasion and interpersonal pressure.<br>○ Offers.<br>○ threats.<br>• Lies are defined as an informal use of restraint; actions done by staff that limit PWD freedom of movement and will; to protect their safety, preventing falls, securing their wellbeing by making them take their meds by avoiding violence and aggression – from the patient towards themselves, but towards the others around them as well.<br>• Concept of *grey zone restraint* – not clearly regulated by legislation, the own staff can't agree if they consider it a restraint or not.<br>• Affirmed how, to achieve more freedom of movement for PWD, more white lies will probably have to be said to them, to make sure they return to the installations, to safety.<br>• There was observed a clear attempt in finding alternatives before subjecting PWD to an informal restraint, that it's still the one that takes away less freedom.<br>• Informal restraints as a way of preserving PWD's life dignity and self-esteem, as they open space for a middle ground.<br>• Logic of choice vs Logic of care |
| **Where are the children? An autoethnography** | Hodge<br>(2021) | Explore if going along with the | PWD in a psychiatric ward of a | • There's only one thing separating deceptive practice from a validating response, which is its intention, doing for the sake of the patient, their wellbeing, with no personal interest. |

| Study | Author / Year | Objective | Study subject | Main Conclusions |
|---|---|---|---|---|
| **of deception in dementia in an acute hospital** (42) | | PWD's reality is a form of deception | large UK general hospital | • It's implied that the response to a PWD can only be defined in the moment, as it's a "lived-time experience".<br>• It's suggested that part of the problem in finding guidance to truth in dementia is also very dependent of the fact that, as observers we can't judge the real time interaction to know what'd be right to do in many cases.<br>• Lying is not condoned, since it represents manipulation and power imbalance. Instead, the study chooses to look at this type of acknowledgment of their reality as a kind of validation of PWD's own reality.<br>• The challenge is to find the middle ground, between the two participants of the conversation and their respective truth, as our truth can be a form of disrespect and take dignity away from PWD and their living reality. |

# Epidemiological Cross-Sectional Studies

The single study analyzed with this methodology helps adding numbers to the concepts and opinions we’ve seen throughout this study: the lie is practiced, and, many times, justified. The difference between the acceptation and the practice of it is explained by the lack of a shared model, and the discussion itself between the medical staff to give the best care to the PWD in question.

Table 4: Selected epidemiological cross-sectional study.

| **Study** | **Author / Year** | **Objective** | **Study subject** | **Main Conclusions** |
|---|---|---|---|---|
| **Lying to patients with dementia: Attitudes versus behaviours in nurses** (43) | Cantone, Attena, Cerrone, Fabozzi, Rossiello, Spagnoli, Pelullo<br>(2019) | What is the the attitude and the behaviour of nurses towards the use of lies to PWD? | Nurses from residential facilities, geriatric, psychiatric and neurological wards | • Consistency of the nurses' attitudes with their behaviours towards PWD.<br>• More than 85% admitted lying in moderation and accept its use.<br>• Situation where lies were less accepted – to save time explaining things to PWD. Only around 50% agreed.<br>• Situation where lies were more accepted by them – when it's in the patient's best interests.<br>• More than 70% refers the importance of a shared model of the use of lies, and the consequent communication needed between the staff, connecting its frequency with the cognitive awareness of the PWD.<br>• Nurses accept lying better than physicians, fact that's justified by the time of care close to the patient.<br>• Lie as a prevention of aggressive behaviour – benefits both the PWD but also the staff. |

# Discussion

By the quantity of articles found, it's understandable that we're talking about an area in need of more attention, observing the lack of studies released on this subject. Many of these articles, published in the last 10 years, use many references from the early 2000's, and some even from the late 1990's.

There's been such a big growth in social and human rights, advocating for a medical practice with more respect, dignity, and patient centred care. An issue to point out is the unclear line socially defined between PWD and older adults, since in our society we're used to think dementia affects purely people in advances ages, that can only frequent nursing homes. Earlier diagnosis, and the delay of the age of retirement creates a shift in this paradigm: more and more, we're witnessing people with some sort of dementia in all types of health situations; some that still preserve some independence but already impaired in their communication abilities.

These patients will have treatments to be explained, consented by them, and done with their cooperation. These people will have conditions - about them and the people around them - that healthcare will have to be prepared to intervene. The need of drawing the lines in the communication established with PWD is getting more important.

The subject of lying and deceiving between PWD is still far behind. As we can see in Hirakawa's study (37), it's referred the difficulty due to the specificity of every interaction with so many different PWD. But we can also see some studies, like Tuckett's (34) and Culley's (35), already trying to bring light to authentic interactions, that even suggest frameworks, although they ended up not being followed. These lift even more questions about our current definitions of deception, lying, between others.

It can be argued that those frameworks were found problematic, and didn't gather an unanimous opinion. Yet, when we check the explanations of the participants that did not agree with them, they still made some valid topics, that should and can be addressed.

Articles like Culley's (35), Turner's (33), Tuckett's (34) and Hirakawa's (37) clearly specify that lying in PWD care is almost universal. However, when it's time to present their arguments defending the technique of therapeutic lying, many of the interviewed take a step back, reticent, not condoning the process of lying and questioning its ethical value.

Culley, Turner and Tuckett (33–35) mention how this can be explained by the lack of formal, legal guidelines, validating lie as the last option of patient approach. This makes the healthcare professionals avoid an open admission of lying. Its formal recognition would not demand their use in every situation but could protect those where nothing else works. Even the ones that do assume the act of untruthful affirmations in their care, reveal their difficulty by the lack of a formal framework.

That same absence of guidelines consequently leads to the approach of the subject as a whole taboo in the medical community, denying the opportunity of sincere, open discussions with the rest of the staff. There's no attempt to reach a point of agreement towards a certain patient, and to validate the therapy choice, helping the health professional to make the necessary decisions more confidently.

Another detail remarked in the found articles is the aspect of lying being more normalised between nurse staff. One of the offered explanations to this bigger normalisation between nurses relies in two big aspects: part is to fulfil their act of care, in an institution that needs rules and inevitable limits, guaranteeing the wellbeing of the residents, towards themselves and the others. They have tasks to complete in a tight block of time, which makes them have something to gain out of a deceptive interaction.

According to Hirakawa, Tuckett, Casey and Hodge (34,36,37,42), the value of lying resides in the intentions towards the PWD. Many (33,36,38,39,41,43) also mention it has implications with the relationship established with the PWD. Healthcare, PWD, and their caregivers, recognise it's different to lie just to "spare time" or to protect the patient from a dangerous situation that can compromise their wellbeing. Independently of the lie itself, it's different if it's towards a PWD the healthcare workers know previously, and do out of protection, or if they invariably lie without knowing the context.

If we focus our acceptance of lying purely in its intention, it may become problematic, as it's not focused on the patients themselves. Despite this, there's other situations where both parts - and even some third parts - have only to gain by those small acts of deception. In the case narrated by Mitchell (40), the deception aiming to the medical adherence guaranteed not only the PWD's wellbeing, but also the safety of the staff and the other residents in the nursing home, protecting them from types of aggression caused by lack of medicine adherence. It's an important case showing how there's an institutional aspect, without abandoning the focus on the patient's wellbeing. Overall, all mention its acceptability when done empathetically, to mitigate the distress of the PWD, as in a way to practice the Principle of Non-Maleficence and causing less harm.

The second dimension of the nurse's interactions with the PWD rests on the fact that they're the ones on the first line of contact with them. There's no other medical staff that knows PWD better; their lives, beliefs, usual behaviours, and even in situations when they don't know, they still have the bigger amount of experience to examine the situations and empirically find the best solution. Alter (38) shows that validation therapy and deceptive actions don't have necessarily to be known as such to be practiced.

All these articles, and their considerations to the meaning we assert to "lying" in these situations can also be tied to Feil's works on validation therapy (24,25): PWD are living in their own stage of life where resolution is a priority. This stage can manifest itself in the most different ways, according to the person, and their beliefs. While being truthful is very important, it often doesn't allow space to consider the situations where truth can bring more harm; and can even represent a direct confront against the PWD. None of the parts has nothing to gain with that said confrontation, as it'll bring more disorientation, pain, and loss of trust in the person communicating with them.

Not telling the truth does not automatically mean we're facing a situation of deliberative lying; especially if the priority is the PWD's wellbeing, if we're empathetically trying to reach what is a problem to them, even if in their own reality, and recognizing it on their side. It's shown in studies like Barbosa's (44) that PWD having their rights recognized and feeling validated has a positive impact in their emotional wellbeing, allowing them to live with more satisfaction. Not disrespecting their reality and allowing them to exist as they are and feel, are also ways to help PWD keeping their dignity; and a very important tool to build a trusting relationship with them. This falls in line with the principles Kitwood (45) established more than 20 years ago.

Another point to consider is how we can see the application of the categories of deception Blum first described in 1994 (20).

Then, Blum defined four dimensions of deception that can more easily be clarified as: going along, not telling, little white lies, and tricks. The idea of *going along*, not challenging the confabulation expressed by the PWD, but giving them time and space to let them to drift away from it by themselves, revealed to be successful in Lindholm's study (39), as it allowed the PWD to feel a full participant of the conversation, not treated as someone with less competences. The nurses in the study practiced this with no previous knowledge.

If we're considering actions like this, there's an important conclusion to take: it can be taught. It may not be innate in every one of us, but the signs and rationale behind these professionals' actions can be studied. In our current society, it's hard, even in our area, to keep our humanity in place. While we need legal and normalised guidance to draw the lines, there's some emotional intelligence needed, to guarantee the lie is in the patient's best interests. These are essential points to reinforce in future studies.

As Hirakawa and Casey (36,37) mention, while the studies done are vital to better understand and make decisions, it won't be enough without a multidisciplinary collaboration, including the ethical and legal part. We can create the most complete studies, but if there's not some kind of legal cooperation, we'll never be able to avoid the professional's reluctance.

Of course, to obtain some kind of legal affirmation, we need to thoroughly review the ethical implications, and the paradigms we're used to implement on patient care. It's understandable the lack of more definitive, general guidelines, seeing how some professionals reacted to the few attempts over the years. We've been following absolute, immutable principles - that should always be accounted for but, despite this, some of them end up being slightly dislocated to the realities we now understand further.

There won't be any approved guidelines if there's no new consensus in this. Our definitions of deception, and therapeutic lying, have been extremely useful so far, but maybe it's the time to review some specific situations, as of the PWD. Despite these absolute principals, all the articles agree to centre their care in the Principle of Beneficence, allowing to practice a patient-cantered care, and to give priority to their living with dignity as living with the minimal distress, in peace, and still inserted in the environment around them, as active interlocutors.

# Conclusions

In the future, our approach to the subject will need, firstly, to consider some questions, with answers that in a black and white world, were previously considered immutable. The attempts done in the past to reform some ethical and moral implications were found to be ineffective also due to this difficulty in seeing subjects in a whole new dimension, potentially considered in a morally grey area. The world keeps turning, and our notion of what is a human being gets more and more complex every day, which demands a widening of our realities from us, that can make a difference.

While useful until now, the need to define better and more thorough concepts like “deception” and “therapeutic lying” grows every day. While we can – and should – keep the focus of our actions in the Principle of Beneficence, we’ve learned with patient-centred care that they may not be such absolute concepts as we idealize them to be now.

We’ll have to, as a society above all, to answer some questions to be able to discuss the rights and wrongs of deception going forward.

As humans, we have our dignity preserved by truth telling at every point of our interactions with the healthcare professionals. As humans, with a dementia, is truth giving them dignity, or is it bringing them distress and instead making them lose quality of life?
If the truth, corresponds to the reality, is our truth theirs, if they live under their own reality that brings them peace?

Is it a lie if the deceptive affirmation doesn’t stay with them long term?

Is it deception, or at least, a bad kind of deception if the healthcare professionals are just agreeing with what PWD consider the truth?

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