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AN ASSESSMENT OF THE THERAPEUTIC FIB:
THE ETHICAL AND EMOTIONAL ROLE OF THERAPEUTIC LYING IN THE
CAREGIVING OF ALZHEIMER'S DISEASE PATIENTS BY NON-MEDICAL
CAREGIVERS

by

DINA J. GREEN

A master's thesis submitted to the Graduate Faculty in Liberal Studies in partial fulfillment of
the requirements for the degree of Master of Arts, The City University of New York
2015



2015

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This manuscript has been read and accepted for the Graduate Faculty in Liberal Studies in satisfaction of the dissertation requirement for the degree of Master of Arts.

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Abstract

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Advisor: Dr. Rosamond Rhodes

This study qualitatively assesses the various aspects of the use of the therapeutic lie in care giving for Alzheimer's Disease patients while examining the ethics of lying associated in and out of the medical setting. The objectives of this study are to: gain an understanding of the role therapeutic lying plays in the care given by non-medical caregivers through a series of focus groups and interviews; examine the moral and emotional issues related to the use of this practice with a focus on non-medical caregivers; gather knowledge of the use of therapeutic lying in order to improve care for Alzheimer's Disease patients. The therapeutic lie is believed to a) be mutually beneficial for both the caregiver and the Alzheimer's patient by easing communication between the two parties; b) cause a feeling of moral ambiguity for the caregiver due to the socially entrenched view that lying is unethical; c) present ethical dilemmas for the caregivers.

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Chapter 1

Introduction

In 1906, when Dr. Alois Alzheimer first described a “peculiar” disease marked by profound memory loss, he certainly would have had no idea of the invasively challenging role it would play in the family dynamic. Today, that mentally degenerative disorder affects approximately 5.4 million people.¹ It causes those affected to experience declines in memory, speech, and motor skills as well alterations in personality and drastic mood shifts, among other behavioral symptoms. It is not uncommon for patients to experience episodes of hallucinations, paranoia and delusions, often times reverting back to former periods in his or her life. The paranoia and confusion may present in forms ranging from asking when a deceased spouse will return home from the store to thinking that his own home is a hotel. Confusion and memory loss, such as difficulty recognizing once familiar objects and people, add to these beliefs. More severe episodes may include outbursts of rage or the patient believing he is being incarcerated. Frequently, the patient is in his own world and his world is ever in flux.

Alzheimer’s Disease progresses through a course of seven stages of changing mental and physical ability (Table 1.1). With each stage comes a unique series of challenges for both the patient and those close to the patient. From detection, usually around Stages 2 or 3, through Stage 6, the mental metamorphosis raises a tangible communication barrier in how family

¹ Alzheimer’s Association. *2011 Alzheimer’s Disease Fact and Figures*. Chicago, IL: Alzheimer’s Association, 2011.

Table 1.1: Stages of Alzheimer's Disease*

- *Stage 1: No impairment*
 - Appears to have normal function
- *Stage 2: Very mild decline*
 - Memory lapses and what may appear to be age-related mental decline
- *Stage 3: Mild decline*
 - Difficulties are more easily noticeable
 - Issues with short-term memory,
 - More difficulty with performing tasks in social settings,
 - Difficulty with organization and remembering the placement of important objects
- *Stage 4: Moderate decline*
 - Trouble remembering recent events
 - Difficulties with complex tasks such as handling finances
 - Impaired memory of personal history
 - Trouble with arithmetic
- *Stage 5: Moderately severe decline*
 - Larger gaps in memory
 - Begins to require aid with daily activities
 - Difficulties remembering personal information such as own address or telephone number
 - Issues with simple arithmetic
- *Stage 6: Severe decline*
 - Personality becomes altered
 - Trouble remembering those close to the patient
 - May wander or become lost
 - Increased suspiciousness and delusions
 - Extra help required for activities of daily living such as help with the bathroom and dressing properly
 - May have major changes in sleep patterns
- *Stage 7: Very severe decline*
 - Loss of ability to interact with the environment
 - May have decreased control of muscles

*Stages are defined by the Alzheimer's Association

members and friends interact on a daily basis with the patient.² Communication techniques have been created and support groups and workshops have been designed in an effort to aid these non-medical, often family, caregivers in their efforts to care for and communicate with their loved ones and deal with the emotional strains surrounding the task at hand.

The concept of therapeutic lying, also known as therapeutic fibbing, has been seeping into the medical scene over the past two decades. It is specifically designed to ease the path for both the caregivers and the patients in their emotional welfare and communication attempts. This technique focuses on the practice of lying to the emotionally compromised and fragile dementia patient, with the goal of alleviating agitation or distress.^{3,4} To attain the desired result, this means of communication may be categorized in the forms of omissions where there is no attempt to correct the misstatement, “playing along” with the current mindset of the patient, or blatantly telling him an untruth.

While not well popularized as established terminology, many caregivers have been employing this technique subconsciously. Others, when presented with the concept of being untruthful with their loved one, react negatively to the idea—some eventually coming around to it and others not. These rejections from the caregivers stem from two main categories—the moral and ethical stigma against lying and the general denial of having a loved one rapidly progressing

² Feil, N., and R. Altman. "Validation theory and the myth of the therapeutic lie." *American journal of Alzheimer's disease and other dementias* 19, no. 2 (2004): 77.

³ Pekala, Kathryn. "And Grieving." *Dementia, Aging, and Intellectual Disabilities: A Handbook* (1999): 330.

⁴ Stubbs, Brigid. "'White lies' can sometimes be kinder for people with dementia." *Nursing Standard* 28, no. 2 (2013): 30-31.

into such a state of deterioration.^{5,6} The latter is seen most often in the case of caregiver children of parents with Alzheimer's Disease. For many, they are fighting the emotional surrender of admitting that their mother or father is overtaken by an illness to a point at which they can no longer communicate or reason in a "normal" fashion. The parent, or spouse, has become the child. This is a poignant hurdle, one which a caretaker must overcome. The moral block is an internal struggle as well. The bigger picture, however, is what poses potential for a greater bioethical issue.

As mentioned above, therapeutic lying is a newer concept with a soft establishment. Its use by medical professionals, while not heavily represented in the literature, stakes a much larger presence than its use by non-medical professionals. It is often used as a validation for the person with dementia, already suffering with confusion and distrust. In many cases, therapeutic lying can actually create a feeling of safety for such patients, as it can help both patient and caregiver to avoid some of the stress and helplessness that comes with the Alzheimer's territory. There are situations when lying can be used as a tool to reduce agitation and prepare for redirection of the person with degenerative brain disease. It is arguably illogical and unnecessary to try to force someone in the middle or later stages of dementia, cognitively unable to make sense of or recognize reality, to accept your truth. For a mid-disease person, who finds comfort in the belief that he is living in his childhood home along with his parents and siblings, it serves absolutely no purpose to remind him that he is living elsewhere and that his parents have been long deceased.

⁵ Wood-Mitchell, A., A. Waterworth, M. Stephenson, and I. James. "Lying to people with dementia: Sparking the debate." *Journal of Dementia Care* 14, no. 6 (2006): 30.

⁶ Stubbs, Brigid. "'White lies' can sometimes be kinder for people with dementia." *Nursing Standard* 28, no. 2 (2013): 30-31.

Reassurance at this point in his life brings calm and consolation. Instead of thinking of it as denying the person his right to know, occasional use of therapeutic fibbing is considered a benevolent way of easing emotional distress.

While delusions and hallucinations are both common in middle to late stage Alzheimer's Disease, they are essentially different. Hallucinations, centered around perceptions and senses, cause the person to feel, hear, see, or taste something that is not really there. An Alzheimer's patient may believe he is being poisoned through food that looks or tastes different to him, or believe his own caregiver is a demon, based on perceived appearance. Delusions are, simply, false beliefs. For example, a patient may believe that his own spouse is stealing his possessions. Although not the truth, the situation is indeed very real to this patient. Trying to convince him of a reality opposite his belief would only serve to confuse and aggravate him more. A person with dementia is constantly trying to make sense of a jumbled world, and doing so with weakening cognitive function.

Ethics of Lying

Lying is a form of deliberate deception. As members of society, we are brought up with an absolute understanding of the stigma that "lying is bad." It is often one of the earliest and most repeated admonitions for young children.⁷ Being untruthful is often categorized as an immoral or unethical behavior, associated with feelings of hurt, distrust, and perhaps later regret. As humans, we strive to observe and process our surroundings, as they are, in the most honest way possible.

⁷ Richard, Claude, Yvette Lajeunesse, and Marie-Thérèse Lussier. "Therapeutic privilege: between the ethics of lying and the practice of truth." *Journal of Medical Ethics* 36, no. 6 (2010): 353-357.

In other words, we do not relish deception. In order to navigate the world in its physical and social terrain, humans rely on the information they perceive to be the truth. If this information is inaccurate, trouble could be in store. In a basic example, Person A is blind and Person B has full vision. The two are walking and Person A asks Person B if there is a rock before him, as would be expected on this path. Person B purposely tells person A that there is no rock in front of him when this is not the case. Person A then trips on the rock and Person B finds humor in the situation as he expected. Here, one party is harmed due to deception. It might even be argued that the person expressing the deception, unless a sociopath, is harmed as well. This is a traditional view of lying—the association with ethical malpractice.

According to German philosopher Immanuel Kant, accepting lies in a society undermines the collectivity. Kant believed in a universal moral ban on lying to protect the ability of people trusting one another and therefore being able to work together in communities and larger societies. Under the umbrella of therapeutic lying, this idea cannot be supported, since it is an action of empathy. No one other than the two communicators—caretaker and patient—is impacted. In this scenario, the two sole players are impacted positively rather than the negative expectation of Kant. Even this philosopher, though, would agree that one cannot judge an occurrence until he has experienced it. Only the practiced caretaker can provide feedback on the results of communicating through therapeutic lies. Here, "good will" should not be confused with "truthfulness" when it comes to easing suffering.⁸

The usage of deception, or fibbing, does not always necessarily stem from malicious intentions. In order to examine the true ethical nature of the lie, its components must first be

⁸ Bakhurst, David. "On Lying and Deceiving." *Journal of Medical Ethics* 18, no. 2 (1992): 63-66.

examined. As with all communication, the lie may be broken down into three components: the sender, the message, and the receiver. Here, the liar must intend to mislead, information must be communicated, and the receiver must believe the information is true.⁹ The act of knowingly withholding information as grouped in such categorization is highly debatable, but will be grouped as general manipulation for the sake of this discussion, not pure lying, per se. Each of these components possesses the potential for both positively and negatively intended actions. In the above example cited, Person B believed the information he was construing was not truthful, he was indeed communicating information, and his intentions were certainly to mislead, but with the intention perhaps of providing a sort of twisted humor for himself or seeking a form of revenge against Person B. Regardless, the intentions were clearly malicious.

Now, take the same case except there is a poisonous scorpion in Person A's path, but no rock. If he steps on the animal, he will be harmed. Just as in the original case, Person A asks person B if there is a rock before him. Person B replies that there is a rock in front of him when there is in fact solely a scorpion. As a result, Person A adjusts his gait and does not step on the poisonous creature. In this second example, Person B meets each component of lying. The following differs from the first example: a) Person B was not ill intentioned and b) Person A was not only unharmed, but was saved from harm that would almost certainly occur had he not said anything. In addition, it may be said that Person B saved Person A from the fear he might have felt had he known of the real danger afoot.

Despite such an instance with clearly good intentions, each of the abovementioned components, and lying in general, presents a slippery slope in social interactions. In other words,

⁹ Ludwig, Arnold M. "The Importance of Lying." (1965), pp. 156-161.

not all lying is intended to be bad, but should be used cautiously and only with good intentions. Relating to the above scenario, Person B may feel delighted with his ability to have spared Person A, and so use this “technique” as a springboard for other interactions with various people. It would be a philosophical and sociological error to feel that one might universally benefit others by becoming the “Robin Hood” of positive communications. It is part of the human psyche to be able to incorporate often-used behaviors into a personal repertoire with increasing ease.¹⁰ Even when used with good intentions, one may become comfortable enough with the practice and may start to irresponsibly practice lying.

Upon revisiting the second outlined case with the scorpion in place of the rock, one main question arises—Why would Person B not simply tell Person A that there was a poisonous animal before him rather than the nonexistent rock? In this case, it is fair to assume that Person B was both physically trying to protect Person A from the scorpion and from the emotional agitation and panic that would have possibly ensued would he have known that a scorpion was in such a close proximity to him. Perhaps he had a particular fear, or Person B believed he might be more apt to trip if he knew of the danger. However, does this ethically justify Person B’s actions? Perhaps if Person A discovered Person B’s dishonesty he would be equally agitated.

A similar line of analysis occurs when examining a situation in which therapeutic lying is used. Here, though, the recipient of the information or “fib” is an Alzheimer’s Disease patient in a cognitively compromised state. In evaluating this case, it is important to remember that the patient’s mentally compromised state specifically includes a short-term memory loss and reasoning. In truth, the patient most differs from Person A in the previous cases in that the

¹⁰ Hughes, Julian C. "Philosophical issues in dementia." *Current opinion in psychiatry* 26, no. 3 (2013): 283-288.

patient is at a highly decreased risk of discerning fact from fiction or present from past. Surely this does not hold in every situation, but often times, the patient has a decreased ability to reason as well, mitigating his ability to figure out that a lie was told and sometimes even forgetting the topic, moving on to the next. Therefore, it seems that the negative ramifications are minimal when lying, with positive intentions, to an Alzheimer's Disease patient. However, does this open the door for a caretaker's manipulation of the patient? Where is the line between exploitation and agitation mitigation?

As solving bioethical issues is not only a complex, but challenging mission, the decision to tackle the topic of therapeutic lying falls well within this category. The practice of therapeutic lying itself must have stemmed from the quandary of "what to do" to ease the difficult moments for the Alzheimer's patient. While arguably not as final as the issue of abortion or end of life decisions, continued use of this form of interaction has, for better or worse, enduring impact on the caregiver. So common with moral dilemmas emanating from diverse conditions, attempting to solve a particular ethical predicament, such as communicating with a dementia patient, brings other issues to the surface—who is in a position to fib and under what circumstances. As emotionally taxing as it is dealing with the many stages and factors involved in the progression of Alzheimer's Disease, it stands to reason that discussion of this topic by bioethical researchers in tandem with caregivers can serve as an ongoing resource.

As positive communication experiences are a necessary part of the caregiver's task, he must be prepared, without warning or delay, to deal calmly with any request or statement from the loved one in his charge. Take, for example, the following realistic cases:

Case 1: The patient asks about his grandson who lives in Phoenix, Arizona. The grandson lives in Manhattan. Should he be corrected? When engaging in such a conversation with an Alzheimer's patient, one has the following choices. Choose your adventure:

- A. Correct the patient with a *mild* risk of factual pushback. This is under the assumption that the patient would, under a more stable and structurally sound mental state, not be too bothered by his grandson living in Manhattan over Phoenix.
- B. Do not correct the patient and attempt to change the topic to something more pleasant and agreeable for both of you.
- C. Play along and succumb to the patient's world. This does not mean to fabricate trips to the Grand Canyon, but entertain the notion, should questions about his whereabouts be pressed.
- D. Play along and take it to the next level—construct a life in Phoenix for the grandson that he does not have, and likely will never have.

Upon examination of the above choices, Choice D, seems the most unnecessary. While there are no ill intentions, this seems excessive the goal is to mitigate agitation while staying morally composed. Therefore, while Choices B and C are similar, it is probably best to choose B out of the two. Choice A, given, the amount of distress potentially caused to the caregiver from lying, may even be appropriate in this particular instance.

Case 2: What about when the stakes are higher and the patient is at a greater risk for agitation or tantrums? Here are the choices given the patient asks about when his wife, who has been deceased for nine years, will be coming home from the store:

- A. Correct the patient with a *high* risk of factual pushback. You inform the patient that his spouse has been deceased for the past nine years.
- B. Do not correct the patient. Simply attempt to change the topic to something more pleasant for both of you.
- C. Play along and succumb to the patient's world. This does not mean to fabricate the deceased spouses day, but entertain the notion, should questions about his whereabouts be pressed. For example, saying things like, "She'll be back soon."
- D. Play along and take it to the next level—construct a life in present day for the deceased spouse.

Just as in the previous case, Choice D seems like a heavy-handed approach, tipping the scales in favor of unnecessary lying, causing an ethically ambiguous slippery slope. To reiterate, the key is to find the approach that best utilizes the act of deception at its bare minimum. Choices B and C both seem reasonable, perhaps Choice B even more so unless the patient presses for information about the spouse. In that case, Choice C would be best. Choice A, unlike the previous example, would clearly upset the patient. This could spiral into extreme agitation and sadness or a paroxysm. It is certainly possible that the patient could austere respond with a resounding "Oh," upon receiving the corrected information, but this is highly unlikely. In many cases it is as if he is finding out for the first time that his spouse has passed away. For others who are aware they are confused and experience delusions, it may be even more upsetting for them realizing that they have forgotten such a fundamental fact of their lives. The probability for a positive outcome is thin for Choice A here. At the end of the day, unfortunately, the disease will prohibit the patient from remembering the conversation in the first place. The inclination to choose Choice A is for the caregiver more than for the patient. In other words, correcting the

patient does nothing positive for him. It only provides some normalcy for the caregiver. This benefit is not enough to outweigh the potential risk of the situation.

To add an extra layer onto the previous example, let us say the patient has hypertension.

Unless the disease was early in onset, Alzheimer’s patients are most commonly members of the geriatric population and frequently possess systemic ailments associated with high blood pressure, which are known to be

Age	Men (%)	Women (%)
20-34	11.1	6.8
35-44	25.1	19.0
45-54	37.1	35.2
55-64	54.0	53.3
65-74	64.0	69.3
75 and older	66.7	78.5
All	34.1	32.7

worsened by stress (Table 1.2). In sum, this is not an unusual case and agitation exacerbates the condition.¹¹ Now, more so than in the previous evaluation, Choice A seems far less morally ambiguous. A similar case would be telling a patient that the medication he is about to take is his daily multivitamin rather than the antipsychotic he has been prescribed to decrease he frequency and severity of his delusions. Does this mean that anyone with any known condition should be lied to in order to prevent an elevated stress level? No, but surely extra measures of compassion and care in communication should be taken. The compromised memory and general mental

¹¹ Pekala, Kathryn. "And Grieving." *Dementia, Aging, and Intellectual Disabilities: A Handbook* (1999): 330.

status of the patient is a key component to alleviating the moral ambiguity. Under certain circumstances, such as the complexities of caring for the patient with dementia, lying can be quite compatible with therapy. Empathy and concern for the already confused and distressed person is a good guide to distinguishing between therapeutic and harmful intent.

This moral ambiguity translates into the professional medical setting as well. Traditionally, physicians, nurses, and other medical professionals were and are instructed to be truthful and observe full disclosure and respect in practice.¹² The confidentiality between doctor and patient ensures for the ability of full disclosure. Not until the recent decades has there been doubt raised concerning both the act of withholding information and fibbing to a patient. Each is in an effort to provide the best care whether that may be finding balance between emotional sensitivity and delivering the necessary information or taking a “mind-over-body” approach (e.g. a doctor not informing a cancer patient that there is little hope for him and instead remaining optimistic, hoping this may provide him with a high remaining quality of life or possibly aid in his fight of the illness). These techniques were taboo for good reason--If much of healthcare is built on the institution of the sacred doctor-patient relationship, which may as well be a synonym for “trust,” why jeopardize this? Rather, is the doctor-patient relationship jeopardized at all?¹³

Some patients prefer a more coddled approach to their healthcare and would appreciate psychological protection while others want all the facts and hard truths laid out in front of them. While this is not quantifiable at this point in time and the statistics remain unavailable, it could

¹² Higgs, Roger. "Truth Telling, Lying and the Doctor–Patient Relationship." *Principles of Health Care Ethics*, Second Edition (2007): 333-335.

¹³ *ibid.*, 337.

conceivably be that the majority of the population lies in the latter category. Operating under this assumption, it may make sense to take a utilitarian approach and have healthcare professionals abstain from using any form of therapeutic lying. This makes sense in terms of the overall population, but the utilitarian approach changes if the population in question consists solely of Alzheimer's Disease patients. For the reasons outlined above, to alleviate potentially dangerous stress and agitation, perhaps healthcare professionals should engage in this practice of fibbing. Alternatively, this approach could provide an even slipperier slope than in the case of the caregiver. If the patient is in the room with his caregiver, as is often the case, should the physician use a therapeutic lie for both? A medical professional, especially in these times of a litigious society, would be ever mindful of the possibility of a malpractice accusation, regardless of his intention. On the other hand, the Hippocratic oath taken by every physician seems to justify the use of the therapeutic lie to avoid excessive pain and suffering.

When dealing with pediatric groups in healthcare, small fibs are told to patients all the time. For example, "This will only hurt a bit," or "You won't even feel it," said in the moments prior to receiving a shot of some sort. For a child, that vaccination shot may hurt quite a bit—not a little, but a lot. These are minor fibs meant to calm the patient and are accepted as commonplace in medicine. These lines may seem unremarkable and petty, but they are the same genre of communication that is at the heart of the therapeutic lie.¹⁴

The main difference between the use of therapeutic lying by a non-medical professional caregiver and a medical professional is knowledge of the patient and the sheer primary

¹⁴ Nelson, Hilde Lindemann, and James Lindemann Nelson. *The patient in the family: An ethics of medicine and families*. Routledge, 2014. pp. 240-248.

responsibility of the professional to first, and foremost, deliver *reliable* healthcare to the patient. The family or friend caregiver has a greater “right” to employ this communication tactic.¹⁵ Here, the word, “right” is born from the caregiver’s increased time spent with the patient and, more crucially, his greater ability to predict the patient’s reactions. A family member is far more able to properly and effectively use the tactic whereas a physician or nurse should try to avoid as many ethical slippery slopes as possible given the nature of their occupations. As is illustrated later on in the research analysis, therapeutic lying is born out of necessity.

Teepa Snow is one of most influential and experienced educators on dementia of the past 20 years. Ms. Snow holds lectures around the country for thousands of caregivers and professionals on various caretaking techniques and practices.^{16, 17} In one demonstration, Snow walks over to a table set with glasses and a pitcher of water among other refreshments. She looks at the spread and picks up the pitcher of water, lifting it to her mouth to drink. The audience is clearly taken off guard. A woman walks over to Snow and tries to hand her a glass and a napkin. Snow takes the napkin and sticks it in the pitcher, swirling it around. She then removes the napkin from the water and begins to wipe down the table surface. The woman goes to stop her. Snow pauses, looks up and asks, “What is one of the problems sometime by mid disease...Sometimes they are not thirsty when they need to be. What was I just doing? Drinking.” She points out that the

¹⁵ Fan, Ruiping, and Benfu Li. "Truth telling in medicine: the Confucian view." *The Journal of medicine and philosophy* 29, no. 2 (2004): 179-193.

¹⁶ Giduz, E. H., E. S. McConnell, C. J. Sanchez, and D. S. Wildman. *Handbook of geriatric practice essentials*. Aspen Publishers, 1988. 43.

¹⁷ Kyomen, Helen H., and Teepa L. Snow. "Intensive-Team Training to Meet the Needs of Dementia Patients: Positive Care Skills and Routines That Can Help." *The American Journal of Geriatric Psychiatry* 22, no. 3 (2014): S21-S22.

woman had tried to get her to drink from a glass and remove the pitcher for her even though Snow, as a mock dementia patient, was hydrating as is normally difficult and important for her to do. No harm or disruption was caused to anyone or anything. She goes on further to highlight that the only issue present was one caused by the woman who did not think that the situation “looked right.”¹⁸

There are two important comparisons that can be made from this demonstration. The first is the child-like nature manifested in the behavior of many Alzheimer’s patients, which makes way for further parallels to be drawn between certain geriatric and pediatric tactics. The second is the emphasis on letting the patient’s behaviors go, rather than correcting the patient by focusing on his error. Just as Snow demonstrates this in relation to actions, so too is this true for behavior. In the above demonstration, the patient was drinking water, an important and difficult task to achieve at certain stages of this disease in particular. There is no reason to correct this behavior when this would surely result in both agitation and diminished hydration. Snow, a proponent of the therapeutic lie, promotes a positive approach in care giving, which means a methodology with mitigated aggravation.¹⁹

¹⁸ *It's All in Your Approach: Facilitated by Teepa Snow*. Filmed at the University of South Florida, 2010.

¹⁹ Giduz, E. H., E. S. McConnell, C. J. Sanchez, and D. S. Wildman. *Handbook of geriatric practice essentials*. Aspen Publishers, 1988. 42-53.

Chapter 2

Background

While the notion of therapeutic lying has been around for about a century, the research on the topic has more recent roots, starting around the late 1970's and 1980's.²⁰ The focus however has been on the role of lying within the medical and healthcare environment with the fibbing done by healthcare professionals. The following is a summary of the research groundwork related to this topic of study.

Elvish, et al. performed a two-phase study in 2008 on the act of lying in dementia care. The deceptive practices used when overseeing Alzheimer's Disease patients are specifically cited. Therapists were asked to complete a questionnaire for Phase I and to attend a workshop on the topic for Phase II. The results show a positive attitude from the therapists toward the role of lying in care for dementia patients.²¹

In a 2013 study, Culley, et al. administered a questionnaire to 76 psychiatrists in England. The psychiatrists were surveyed regarding their opinions on the quality of communication guidelines for dementia care both generally and in ethical practice. They were also asked whether they had both endorsed the use of lies by caregivers and if they had personally lied to a patient lacking full cognitive function, albeit with his best interest in mind. Of the 38% who responded, the majority of the respondents both used and endorsed the practice of lying and felt

²⁰ Myers, Charles S. "THE JUSTIFIABILITY OF THERAPEUTIC LYING." *The Lancet* 194, no. 5026 (1919): 1213-1214.

²¹ Elvish, Ruth, Ian James, and Derek Milne. "Lying in dementia care: An example of a culture that deceives in people's best interests." *Aging & mental health* 14, no. 3 (2010): 255-262.

that the guidelines required improvement. Approximately half felt that the guidelines offered an ethical example to practice.²²

Tuckett of University of Queensland carried out qualitative research in 2012 on the experience of healthcare professionals with lying to dementia patients. Study participants were nurses (both student and certified), personal care assistants, and allied health professionals from five Australian residential aged care facilities. These professionals were surveyed and were found to promote the act of lying to patients. An ethical analysis was performed and the author offered a four-stage communication guideline. In his model, truth-telling is proposed as the first option while a situational-based lie is recommended as a secondary alternative.²³

Day et al. executed a study in 2011 with a more unique participant population. The researchers set up a two-phase study in which dementia patients were interviewed and re-interviewed on the function of lying in care for dementia patients. The authors created a guideline model born out of the intricacies of the data collected. Overall, the participants supported lying within the context of good intentions and specific stages of cognitive state of the patient.²⁴

In a slightly older study from 1994, Blum explores the deceptive practices utilized in the family home of an Alzheimer's Disease patient. This four-year longitudinal study followed

²² Culley, Helen, Robert Barber, Angela Hope, and Ian James. "Therapeutic lying in dementia care." *Nursing Standard* 28, no. 1 (2013): 35-39.

²³ Tuckett, Anthony G. "The experience of lying in dementia care A qualitative study." *Nursing ethics* 19, no. 1 (2012): 7-20.

²⁴ Day, Anna M., Ian A. James, Thomas D. Meyer, and David R. Lee. "Do people with dementia find lies and deception in dementia care acceptable?." *Aging & mental health* 15, no. 7 (2011): 822-829.

family caregivers and collected data through participant observation in support groups and in-depth interviews with over 50 subjects. Blum notes the manifestation of Alzheimer's Disease as a full family struggle and concludes with the difficulties associated with employing the deceptive technique.²⁵

These studies only represent a sampling of qualitative investigations on the topic of deception in care giving for patients with one form or another of dementia. Most of the available research places much focus on the role of lying in the practice of the healthcare professional. Few studies with a focus on the non-medical setting such as the ones executed by Blum and Day have been further researched. These two are distinct in their objectives to analyze the bigger picture of caretaking for dementia patients. What is lacking is a more modern and thorough analysis of therapeutic lying from the perspective of the caregivers who must employ the tactic most frequently.

The efforts of this study are aimed toward shedding light on the impact of the therapeutic fib on both patient and caregiver from both a practical and ethical perspective. From the perception of the family members, it is understood that there would be conversation around the ethical dilemma surrounding use of such a tool, but I never expected the responses to include the tremendous outpouring of emotion and actual gratitude for raising the issue and allowing free expression. Lying can be categorized as therapeutic when the goal is to eliminate damage, especially to an already distressed person. Ethical theorists might determine that use of the therapeutic fib is actually a suitable and virtuous strategy in behavior management when used judiciously. The study of the use of therapeutic lying in relation to the Alzheimer's patient is

²⁵ Blum, Nancy S. "Deceptive practices in managing a family member with Alzheimer's disease." *Symbolic Interaction* 17, no. 1 (1994): 21-36.

important because it takes a socially accepted principle, namely telling the truth, and turns it on its head.

In practice, the goal in using this technique is simply improving the life experience of a person for whom there are now only moments of memory. The role of the caregiver is just that – providing care through compassion and support, whether physical or emotional. When the patient is afflicted with dementia, the caregiver himself is often in need of various forms of support, including physical, financial, and emotional. Studying the use of the therapeutic fib by non-medical caregivers not only validates this type of interaction, but also allows for confirmation that it is exactly as its designation states – therapeutic. The circle of those impacted by the disease is wider than the patient alone. As professionals, it is imperative that we study the practice and publish our findings so that we can do for these burdened caregivers what they are doing for the elderly and infirmed. If this project opens the door to further discussion or investigation, or allows even a handful of non-medical caregivers to feel ethically relieved, its significance will be evident.

The purpose of this study is to evaluate a common communication technique that would normally be morally and socially frowned upon in other situations. While both medical and non-medical caregivers of Alzheimer's Disease patients use this technique, there has been little research on the use of therapeutic lying by those with a close non-professional relationship to the patients.

This study qualitatively assesses the various aspects of the use of therapeutic lying in care giving for Alzheimer's Disease patients. The objectives of this study are: a) To gain a better understanding of the role therapeutic lying plays in the care given by non-medical caregivers

through a series of focus groups and interviews. b) To examine the moral and emotional issues surrounding the use of this practice with a focus on non-medical caregivers. c) Gather knowledge of the use of therapeutic lying in order to better care for Alzheimer's Disease patients.

Specifically, the hypothesis is that the use of therapeutic lying; a) is mutually beneficial for both the caregiver and the Alzheimer's patient by easing communication between the two parties; b) causes a feeling of moral ambiguity for the caregiver due to the social stigma that lying is unethical; c) presents various ethical dilemmas for the caregivers.

Methods

The data for this study were collected through a series of organized discussion-based focus groups and one-on-one interviews both in person and over the phone. Additionally, an anonymous demographic questionnaire was distributed at the beginning of the meeting. Each focus group and interview consisted of adults considered to be non-professional caregivers of Alzheimer's Disease patients (i.e. children, siblings, and partners of the patients)

Approximately 7 participants were surveyed over the course of 3 focus groups and one interview. Participants were comprised of 3 women and 4 men over the age of 18. Participants fall in the age range of 40-70 years of age. Based on a survey of previous focus group-based studies, this sample size should be sufficient for providing pieces of qualitative insight into use of therapeutic lying by non-medical caregivers.

The focus of this study is on the experience of non-medical professional caregivers. Therefore, each subject must consider himself to currently or previously have been an Alzheimer's Disease patient caregiver. There will have been no professional relationship between

this caregiver and the patient. Medical professionals who fall under this categorization may be included if they have experience providing care for an Alzheimer's patient in a non-professional setting. Subjects are all adults and mentally competent. Subjects under the age of 18 or who are deemed to be not mentally competent (i.e. do not exhibit the ability to grasp an understanding of the study or his or her role in the study) as determined by the PI were to be excluded.

The main form of subject recruitment was facilitated by the Alzheimer's Association New York City. The Alzheimer's Association advertised information about the focus groups via email and flyer. This information was be distributed to previous and present Alzheimer's Association New York City Caregiver Workshop participants in addition to the Alzheimer's Association New York City support group leaders. The leaders advertised the focus groups to the support group participants. The groups to which this information will be broadcast mainly consisted of adult children and spouses of Alzheimer's Disease patients (non-professional caregivers). Fliers were also distributed to support group participants associated with memory care facilities in the New York City and Long Island area by the family caregiver support group leaders.

Each individual focus group consisted of two participants. The focus group began with the acquisition of oral consent distribution of the Demographic Survey Form.²⁶ After each participant has completed the survey, the audio recording device was set to record. The PI continued with an introduction as written on the attached Focus Group Discussion form. A guided discussion as outlined on the Focus Group Discussion form is led by the PI for 30-45 minutes. This procedure is repeated for two additional focus groups and one interview.

²⁶ See Appendix A

The entirety of the research poses a minimal risk. The main risk posed is a breach of confidentiality. As with any focus group, a participant may reveal identifying information about a fellow subject following the focus group. Additionally, due to the sensitivity of the topic, some participants may experience some emotional discomfort.

The utmost precaution was in place with respect to retaining anonymity in the study. Each subject will be unidentified during the recordings and the Demographic Survey is completely anonymous. Additionally, access is highly restricted to the recordings. Non-disclosure information will be stated during the introduction as stated in the Focus Group Discussion Form.²⁷

This study only consists of focus group discussions and a survey. At no point should any of the participants be subject to any physical harm or extreme emotional harm. Due to the sensitivity of study topic, some emotional discomfort may occur, therefore posing only a minimal risk. Additionally, all components of the research are completely anonymous.

Results from this research will potentially contribute to the care given to Alzheimer's Disease patients and better provide patient caregivers with the proper communication tools. This will aid in improving the lives of the patients and their loved ones in a time of great difficulty.

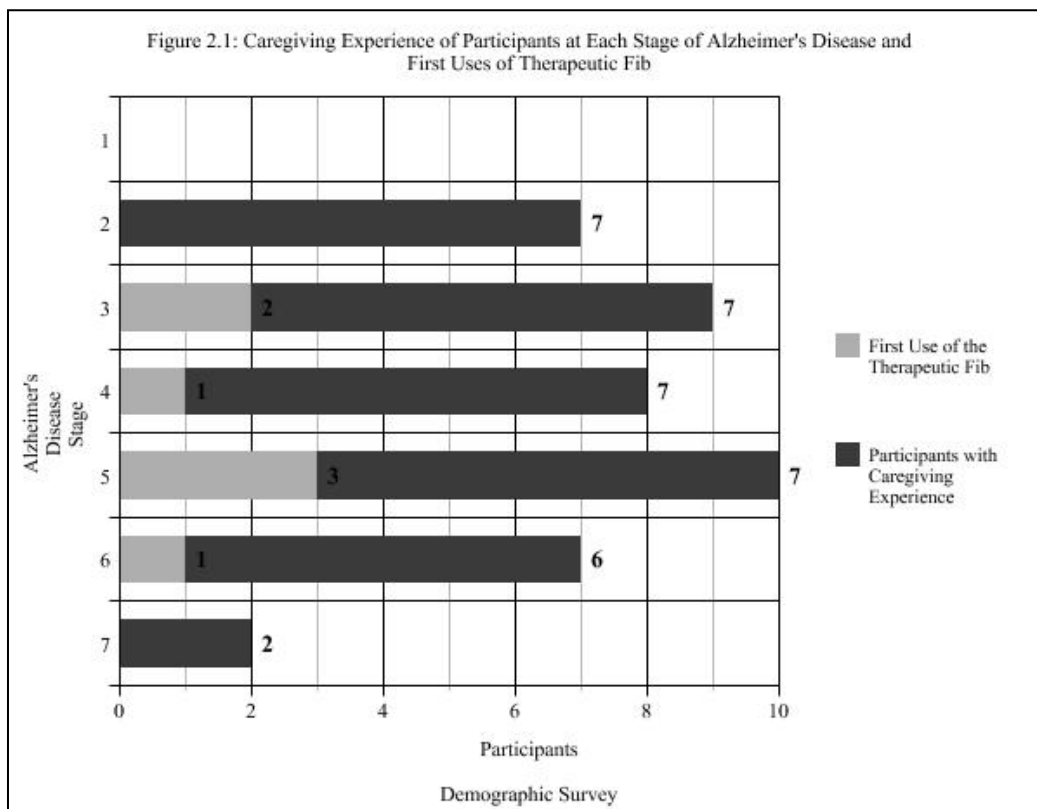
Names will never be collected at any point in the study including the recruitment process, consent process, and research procedures. Subjects will be de-identified during the focus groups and on the audio recordings. Non-disclosure information will be discussed before beginning each focus group. The surveys distributed at the beginning of each focus group are completely anonymous.

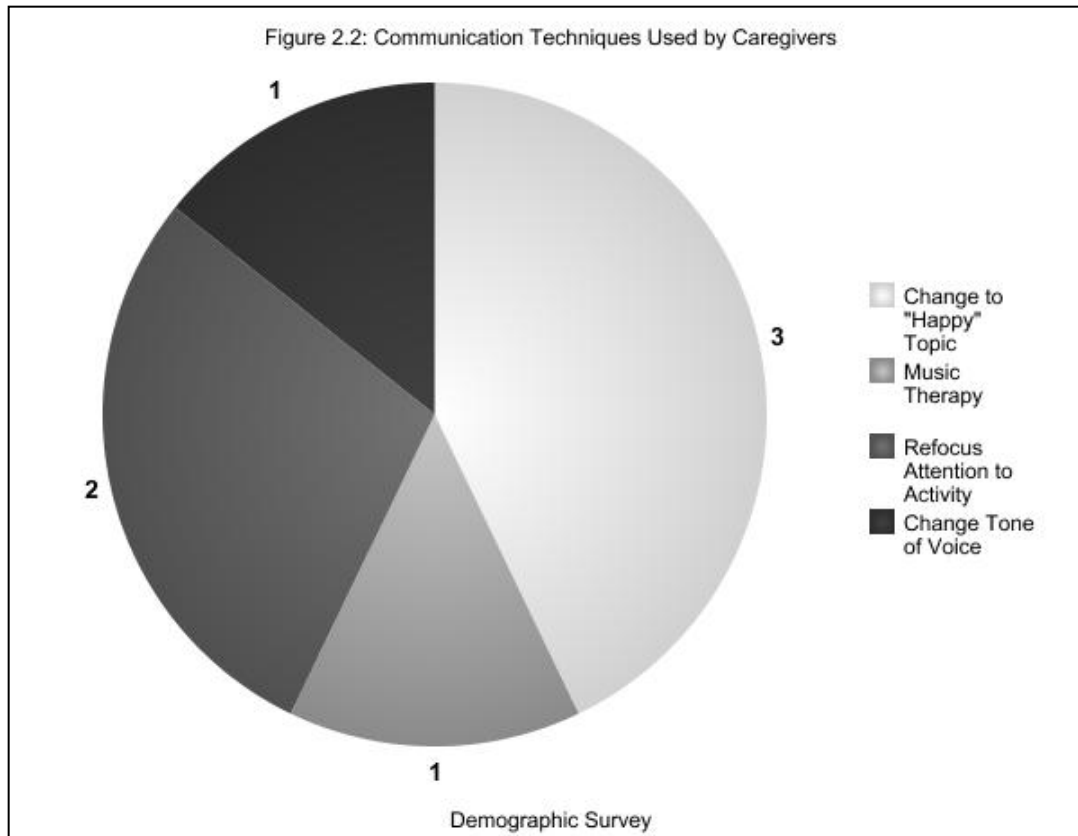
²⁷ See Appendix B

Subject data includes audio recordings of the focus groups and surveys. Main access to these materials is solely given to the PI. Only the Research Advisor and Research Assistant may have access to these materials on a need-to-need basis. Participants are informed of the anonymity of the study and importance of non-disclosure upon leaving the focus group.

Results

The following is a summary of the reactions of the combined focus groups and interviews on a question topic basis. The probes for each topic may be found on the Focus Group Discussion Form. These results will be supplemented by the results of the Demographic Survey as also summarized in Tables 2.1 and 2.2:





Question 1: What experience do you have in care giving for an Alzheimer's patient?

Of the seven participants, five reported to be a caretaker for a mother and two reported to be a caretaker for a mother-in-law. The time for which the participants were actively taking care of their respective patients ranged between approximately 1-20 years, although most of the participants care experience fell between 2-6 years. Two individual participants noted that they had experience growing up with their own mothers caring for a grandmother over the course of several years, eventually in a Stage 7 state. By this point, both participants understood the patients' communication skills to be in a rapid decline. The participants reported to have experience caring for their respective parents and in-laws from the beginning of the

manifestation of Alzheimer's Disease through approximately Stage 7 (Table 2.1). Two participants have experience caring for one's mother through the final stages of the disease until the end of her life.

None of the participants were the sole caretakers for the patients. Three of the participants reported to being secondary caretakers while the rest testified to being primary caregivers. Each of the caregivers received some form of help in their care giving whether by professional aide, a memory care or nursing facility, or another family member. Two of the secondary caregivers lived several states away from the location of the patient. One of the three who reported to be a secondary caretaker for her mother, shared that she would visit her brother, the primary caretaker for her parent, and help by cleaning his home and tended to her mother on a one-on-one basis. Another would visit his mother every few months and would both call and receive calls at all hours of the day on a regular basis. The third acted as a support to his wife, making regular visits to his mother-in-law with his spouse and aiding in care research.

Two of the participants entered the discussion with professional medical experience as a supplement to their personal care giving experience. One had communication as a speech therapist and had completed coursework on dementia. The second, and more notably, shared that he was a primary care physician taking care of the patient in question, his mother-in-law, both professionally for a period of time, but mostly on a personal care level. This is important to note given the nature of the research to examine specifically non-medical professional caregivers. He conveyed that his interactions and care with his mother-in-law were primarily non-professional.

Additionally, throughout the beginning of the organized discussions, a majority shared that research was preformed and help sought after in an effort to learn more about the disease

and beneficial caretaking techniques. The Alzheimer's Association and several support groups served as a primary resource for participants.

Question 2: Have you heard of therapeutic lying?

Three out of the seven participants reported to have previously heard of the term "therapeutic lying." Knowledge of this term was obtained through family members, memory care professionals, and literature provided by the memory care facility. The remaining participants as well as those already informed of the terminology, claimed to be familiar with the concept of the therapeutic fib, but not as a clinical term. One participant claimed a disinterest toward the term due to the use of the word "lying," followed by an admission that she had been practicing the technique. She noted that she had never considered it to be being untruthful. Another participant noted that she tried to initially avoid using the technique and attempted fibbing as little as possible. She conveyed that at one point she realized the necessity for the good of her mother to practice the therapeutic lie. Others reacted in a positive manner toward the term, reporting that it is a logical and apt appellation. Each shared that he understood the need for such a practice in Alzheimer's Disease care giving.

Question 3: Under what circumstances would you consider telling a fib to a patient?

Unanimously, the participants noted that if there is a reward to be obtained from utilizing the technique of therapeutic lying, it is knowing that the patient is more comfortable and content. A few reported if there is any downside, it is purely for the caregiver. Whether for the participant personally or as a theoretical downside, it is the reflex not to lie, especially to a parent, and the emotion hurdle of overcoming that which is the greatest difficulty surrounding this technique. One conveyed that this feeling eased when she realized her mother would not have recollection

of the conversation. It was clearly, for them, a momentary fix. Therefore the conversation would have no further effect on her mother past the point of it providing calming information.

Another shared that the simple act of not agitating his mother was the reward. Others stated that there is no risk at all involved with the use of the practice. The comment was made that the practice is more about not correcting the patient. Additionally, it was pointed out that, from that participant's experience, there should be no negative experiences associated with therapeutic lying since it is never performed in a malevolent manner. It's not in the nature of the action.

Question 4: At what stage in the illness did you begin/would you begin fibbing to the patient to avoid agitation?

Most of the caregivers, while having difficulty reporting the exact stage at which they started to use the therapeutic lie, or similar methods, claimed to begin using a milder form of this technique around Stages 2 and 3 of the disease, as the Alzheimer's Disease begins to pick up intensity in its cognitive metamorphosis. One believed that she began truly using the therapeutic lie at around Stage 5 of the illness—a stage at which she found she could not get around using it, sharing that she wishes she would have used it earlier. One participant found himself avoiding certain topics of conversation and making a generally larger effort at creating a more harmonious emotional space for his mother. He noted that he noticed himself struggling with using any form of deceit about a year ago when his mother, now in approximately the Stage 6 of the illness, as he shared, was in an earlier stage of the illness (estimated to be around Stage 3 of the illness).

For nearly all of the participants, the point at which they found their parents or in-laws possessing the mild to moderate states of an inability to care for themselves was the point at

which they knew that a change had to be made in their interactions with the patient. This was in addition to observing an increased level of ease of agitation. One participant became quite emotional during this topic. She emphasized the internal struggle with avoiding any harm to come to her parent and “doing right” by him, or not engaging in a practice such as lying. The majority of participants revealed that while at first the deceit is difficult, one quickly becomes accustomed to using it. Others revealed that they saw the immediate benefits of using the therapeutic lie and began using it without either realizing it or giving it a second thought. One conveyed that he needed a management tool.

Question 5: What is your biggest concern about withholding information from the patient?

There was some discrepancy under this topic regarding whether or not withholding information from the patient constituted use of a therapeutic lie. The purpose of this question was to gain insight into the caregivers’ general opinion of withholding information, possibly delving into whether it should be categorized in the same fashion as lying. A general opinion on the act of withholding information could help better define therapeutic lying and develop techniques to aid in care giving.

One participant failed to see a connection between the two topics of lying and withholding. Two participants found a direct connection between therapeutic lying and the action of omission in that they are both used for the same reason—to ease the agitation for the patient. Another noted that his concern is based in an instance with multiple caregivers which would pose a higher risk of inconsistencies should some decide to employ the therapeutic lie and or withhold information, and the others decide against it. Overall, participants reiterated their approval and the necessity of the need to both lie and withhold certain pieces of information.

Question 6: When the patient becomes confused and says things that are untrue, do you typically correct him/her? Do you respond as if you are accepting the patient's reality?

Almost all of the participants shared that they each corrected their mother or mother-in-law toward the beginning of the disease's progression. For some, the transition from correcting to not correcting occurred during the transition in the patient's placement from a home setting to a care facility. Only one of the participants conveyed that he wanted to maintain reality for as long as possible and attempts to choose about what to correct his mother to the best of his ability. On the opposite side, another participant shared that she immediately delved into the patient's world and did not think of correcting her, which posed an emotional challenge.

Some participants provided examples in which they either choose to correct or not to correct the patient. The following is an excerpt from the Focus Group 01:

Yeah, sometimes I have to think for myself, personally, something I'll say you know...my mother may forget I'm living in Florida, so I'll remind her that I'm living in Florida. Is it necessary to say that? No. But I'll try to maintain some sort of a little bit of reality so that she can live, and keep maybe, a toe in those waters of reality. So she'll say, 'Oh. That's right, you love Florida, and you love the weather', and so forth. So I pick and choose when to correct a flaw in the, in her reality.

...Well then if my mother says, 'my address is in Brooklyn, right?' and then the question is, well, do I just say 'Right.' And appease her, or do I say, 'Queens. You live in Queens.' So that's a process. Each particular sentence or item has to be dealt within and of itself.²⁸

²⁸ See Appendix C1

The following is an excerpt from Focus Group 03, providing another poignant example of when and how these caregivers choose traditionally deceptive techniques in their interactions with the patients:

You know, if she tells that, you know, that she thinks that she is living somewhere else, if she tells me that she's been living there for a week, instead of the six months that it really is, I would never correct that because that's fine that she thinks that. When she tells me that – when it's something that agitates her, then I correct her. And that's the only time that I do because then there is a reason to. If she tells me that all the people sitting around her are in her apartment and we're not inside it, and it's very important to her to get them out immediately, then I correct it, because it could create a really bad situation for her as well as the other residents. So again, that would be the only time I would correct her. She has told me that she was married to one of the men who was there, all kind of things and I say 'Oh, that's nice.' It really doesn't serve a purpose to correct her. The truth is, she's happy in this, in this environment, in her own world, that's great because, you know, that's what I want. I want her to be happy with whatever she can be at this point.²⁹

In each of the above selections, the caregivers depict situations in which they must select their mode of action in communicating with their respective mothers. The first quotation illustrates the instance in which the correction to his mother is made in an effort to retain his own reality. The second quotation shows an occasion when the participant's mother was becoming agitated and

²⁹ See Appendix C3

she, as well as those in the surrounding environment, may be negatively affected due to her uneasiness should the participant have chosen to forego correcting her mother.

Question 7: What is your opinion on the use of therapeutic lying by medical professionals?

This topic provoked mixed responses from the participants. In regard to specifically doctors using the therapeutic lie, some conveyed a sense of apprehension of a physician utilizing a technique associated with lying. Others promoted the idea under the conditions that a relationship has been built with the physician over a lengthy period of time (i.e. not a first time visit with the healthcare professional), the caregiver had discussed such arrangements prior to the meeting, or that the lies are not associated with the patient's healthcare.

It was shared that this concern is born out of the fear that the physician does not have the patient's emotional interests at heart, as does the caregiver who additionally has a general sense of and ability to anticipate the patient's personality and reactions. One excerpt from Focus Group 03 helps illustrate the caregiver's point:

Well my concern, I actually can tell you, I was with her when she had to go into the physician at the facility and they wanted to give her a flu shot. And she didn't want to get the flu shot at that time. She thought it was nighttime, whatever the reason, she didn't want to get it, and he said – he made something up that he was going to – he said to her, 'Okay, then you don't have to get it.' And then he said to me, 'We'll give it to her when she's sleeping.' So she heard – you know with her memory as bad as it is, she heard him say one thing to her, and then immediately following, but with the truth, to me, and that was a really bad thing.

So again, if it's not someone who is sensitive to that person's needs, and really... it depends who the person is. Usually the aides are very, very caring and get to know the person. But I don't believe that a doctor should use the therapeutic fib, unless it's just to calm the person that everything's okay. The "everything's okay" thing I think is good.³⁰

The caregiver experienced a situation in which the patient had caught the doctor's lie. As a physician, in this instance, who was not too familiar with the patient, maybe 2 or 3 visits total with the caregiver's mother at this point, as she later told me on record, he consequentially caused the patient distress in a situation in which he attempted to do the opposite. The caregiver notes the differences between the roles of the professional medical aide and the physician—how the aide is with the patient on a constant basis and usually possesses a certain emotional intelligence, rather “very, very, very caring,” possibly in a way found more often in those of that healthcare role versus that of a doctor.

The following is a compelling and important case provided from the participant of Interview 01 in favor of working with the physician:

I can tell you the technique that I developed with my mother's geriatrician. And it took time for me to figure this out...So the agreement that I had with the physician was that while he was with my mother examining, I was with her the entire time...But I would not interrupt any conversation that he had with her. I would not insert myself into any conversation or situation; I would just sit there and take notes. Because he would ask her questions, she would answer, or a lot of times the answers were not accurate, but in many cases he could not have known that. When I got home that evening I would transcribe my

³⁰ *ibid.*

notes and I would send those notes to the physician so that he would know exactly what was accurate and what wasn't accurate in that visit. And it took me a while to kind of figure out that this needed to happen, but once we got the rhythm going, it was excellent...It worked really, really well.

And what I said to my mother was, each time, 'Now, you know, when we go to the doctor, I never remember what he says. Do you remember what he says?' And ordinarily, you would never say to an Alzheimer's patient do you remember something, but this was an instance in which I could say, 'Do you remember all the stuff he tells you, cause I don't remember it.' And she could say no she didn't remember it. I said, 'So I'm going to take notes, okay? You sit – you have to talk to him. But I'm going to take some notes so that we can go over what he tells us to do when the visit is over.' And she would say, 'Okay, that's a good idea.' And of course I would have to repeat what we were going to do each time, and it worked. In fact, it worked very, very well...But I also had a cooperative geriatrician.³¹

Here, the caregiver shares his experience in working with the physician to essentially act in a deceptive manner in an effort to have his mother believe that she is “in control.” In other words, that the patient was at ease in what could be an otherwise tense situation. The participant with previous healthcare experience speaks to these points as well.

Additionally, the participants discussed the terminology as a clinical construct. While the term of “therapeutic lying” or “therapeutic fibbing” was not reported to have an impact the decision of each caregiver individually in his or her decision to utilize the technique, no one

³¹ See Appendix C4

expressed any negativity toward the terminology. Instead, the participants unanimously felt that having a clinical term or technique in place may encourage those caregivers who disapprove of being untruthful with their loved ones to use this helpful practice. As stated in Focus Group 02, “...Therapeutic lying sounds like some medical term that absolves you of all personal guilt in the lying. And that’s OK because the caregivers have to feel comfortable too, not just the patient.”

Discussion

The data collected in this study supports the use of the therapeutic fib by the non-medical professional caregivers of Alzheimer’s Disease patients. The participants have each spent ample time, some more so than others, caring for either a parent or an in-law. Each participant had experience with the patient from diagnosis through an advanced stage of the disease. When weighing the positive versus the negative effects of the technique, the participants have unanimously ruled in favor of the positive. The benefits of placing the patient as far from an emotionally harmful or agitating situation as possible outweighs the ethical backlash or “kneejerk reaction,”³² of the technicality of lying and the emotional strain this causes for the caregiver. A participant from Focus Group 02 related her observation of a family situation occurring in the care facility where her mother lives:

There was a family who had just put their- just registered their mother in this [Ed. memory care facility], and they were beside themselves because they said they can’t leave, and the mother is saying, ‘Don’t leave me here! Don’t leave me here!’ And they said, ‘How do you get out?’ And everyone in the room said you have to lie to them. You

³² See Appendix C1

say you're going to the bathroom; you'll be right back in; you have to get your purse. And the girl was irate. She said, 'I will never say that! I will never lie to my mother.' And it was a very interesting thing, because at that point I had just started having to do it myself. And I thought to myself, you know, give it a few weeks, because you won't be able to survive.³³

As illustrated from this selection, the therapeutic lie is viewed as a necessity to “survive” the commutation turmoil that is Alzheimer’s Disease. At the beginning, the practice is difficult for the caregiver. While participants cited an internal moral struggle as noted above, this intricacy could also be attributed to a state of denial, in this study, on the child’s part.

It is a hardship to bear witness to the cognitive, emotional, and physical decline and deterioration of any loved one, especially a parent. Changing the way in which communication occurs with a family member could be easily translated into a sign of submission and admission on the part of the caregiver. It is not only the physical things that are said, or rather not said, that change, but often the ways in which they are said. For some caregivers, the tone in which they speak with the patients can become childlike. A glimpse of this was seen in the abovementioned excerpt cited from Interview 01. He spoke of his visits to the doctor with his mother. Toward the end of the segment, he relates a dialogue with his mother that is reminiscent of a parent speaking to his child, not a child speaking to his parent. However, this excerpt is certainly nothing more than a glimpse of such behavior within the context of this study. It should also be noted that this tone is not presented to be a negative or demeaning form of conduct on the part of the caregiver, but merely another calming tactic to place the patient at ease. This behavior can be witnessed

³³ See Appendix C2

during family visits in nursing homes and memory care facilities alike and utilized by the care staff with the patients as well. Similar to the insights regarding current communication about which many of the participants spoke, this tone seems to arise almost involuntarily.

What was found to be most unexpected about the data was the lack of focus on the advantage of the therapeutic fib to the caregiver. Most of the discussion was concentrated on how much the technique improved the life of the patient rather than on his or her own. Only a few snippets of discourse emerged from the discussions highlighting the mutual benefits of the therapeutic lie to both the caregiver and patient. This could be attributed to a sense of compensation and guilt felt by the caregiver for the use of the technique—an initial emotion which surfaced during the discussions. It could also be exemplary of the selflessness in how much these caregivers have given to maintain the quality of life of their parents. This selflessness among the participants was clear from the presented data and an important hallmark of the character of a family caregiver, especially primary—a testament to intentions in caretaking.

The relationship between the caregiver and the patient is the key distinction between the use of the therapeutic fib by a loved one and a healthcare professional both in struggle and practice. The comparison is an important piece in understanding the role of the technique in the lives of those outside of the healthcare profession. The ethical dilemma of lying presents itself in each situation, but the internal resistance of speaking to a loved one in such an altered manner as outlined above is not a consideration on the part of the healthcare professional. While this study, in one of its limitations, represents only a small fraction of Alzheimer's Disease caregivers, it still represents the views of seasoned non-professional caregivers. These are men and women who have been in the trenches as dementia claimed the person who was a loving parent. It is hard to imagine that a significant part of the population would not share in the same sentiments toward

those in the medical profession utilizing the therapeutic fib—to proceed with caution. The data does not reflect that medical professionals, with a focus on physicians, should not completely abstain from lying, but should shy away from it. A participant from Focus Group 01 stated, “I don’t like the idea of anyone lying to my mom, but that’s a protective, a family protective thing – protecting, but like I said at the end of the day, everything is about the quality of life and quality of care of the patient.” It can be especially troublesome to family members when practices associated with ethical malpractice take place in the same setting as sensitive health information. More so, it is often employed by individuals who are far more unfamiliar with the patient than the caregiver. However, when executed properly and with a trusted professional such as a long-time physician with emotional intelligence or a caring and reliable nurse or medical aide, the outcome can be highly beneficial to the patient’s care.

Both the person practicing the therapeutic fib and the concrete practice of the technique share a required attention. The choice to omit information and correct the patient when communicating must be a careful one. As discussed earlier, there are situations in which it is counterproductive to engage in the therapeutic fib. The main instances where this holds true are when the fib will lead to greater agitation for the patient and his surroundings or when the fib is easily figured out in the moment—each only causing more distress and perhaps escalation of unwanted behaviors. At its heart, though, the technique is purely intended to be used in a positive, non-malicious manner.

This is where the decision of how and when to use the therapeutic lie departs from the stigma and enters true ethical dilemma. According to the study, immoral association with lying is what brought upon initial guilt and apprehension either before employing therapeutic lying or upon realization that the technique was being used. If much of the basis of morality and ethics,

bioethics in particular, is to reduce distress to the more vulnerable party—the patient—and all other associated parties if possible, then therapeutic lying, when used properly, surely fits into an acceptable ethical framework. It is even arguable that it is unethical not to employ this technique on the part of the non-professional caregiver. Like many communication techniques, it is the misuse and unnecessary deception of the patient where the ethical slippery slope lies—a place posing even more danger to a healthcare professional. To prevent this, guides and models should continue to be developed based on further research to aid caregivers throughout the progression of the disease affecting their loved ones.

The limitations of this study include the following: a small subject sample size, self-reporting, lack of cultural diversity, lack of Stage diversity among the associated patients, lack of diversity in the relationships of the associated patients to the participants, and slight inconsistencies among the presentation of probes within the focus groups and interviews. If repeated or should follow-up studies be conducted, the study should include a larger and more diverse subject population. This would result a more representative data set. Additionally, insights would be gained on the topic from a multi-cultural perspective, having more widespread implications. Both the Stages at which the caregivers have experience interacting with the patients as well as the relationship of the patients should be diversified in an effort to create a more accurate depiction of the communication experienced by the caregivers at different levels.

Conclusion

As aptly stated by the participant of Interview 01, “You can’t win the argument, so don’t have it. It’s that simple.” Perhaps further investigation into this area might even have an impact of changing the accepted psychosocial interaction with dementia patients. While it is the objective of every decent caregiver to protect the person in his charge, doing so might mean relating to a demented person in more social terms. Attempting to join him in his world encourages continued communication, at whatever level possible, while forcing an alternate, albeit true, reality serves no purpose. It is impossible to drag a person with compromised cognition into our world, yet it is simple for us to preserve the patient's dignity and peace by entering his. Instead of thinking of the fibs, whether of omission or words of deceit, as disrespecting the person, caregivers and ethicists must see this practice as what it provides. The safety and comfort of the person for whom we care is of utmost importance, and surely the positive experience is, in this case, an important moral maneuver. By focusing on the benefit for the patient, the caregiver is rewarded, too, by moments of easy interaction.

Appendix A: Demographic Survey

1. **Age:** 18-35 36-45 46-55 56-65
 66-75 75+

2. **Gender:** _____

- Race/ Ethnicity:** Black White Asian
 Latino/Hispanic Native American
 Other: _____

3. Do you currently care for or have you previously cared for an Alzheimer's disease patient? Yes No

For how long have you been caring for this person?

- Less than 6 months 6 months-1 yr 1-3 yrs
 3-5 yrs 5 yrs +

4. What is your relationship to the patient? (If you have provided care for more than one Alzheimer's disease patient, please answer for the most recent patient.)

- Spouse Mother Father Mother-in-law Father-in-law
 Aunt Uncle Other: _____

5. What is the stage* of Alzheimer's disease of the patient?

Stage 1: No impairment

- Appears to have normal function

Stage 2: Very mild decline

- Memory lapses and what may appear to be age-related mental decline

Stage 3: Mild decline

- Difficulties are more easily noticeable
- Issues with short-term memory,
- more difficulty with performing tasks in social settings,
- Difficulty with organization and remembering the placement of important objects

Stage 4: Moderate decline

- Trouble remembering recent events
- Difficulties with complex tasks such as handling finances
- Impaired memory of personal history
- Trouble with arithmetic

Stage 5: Moderately severe decline

- Larger gaps in memory
- Begins to require aid with daily activities
- Difficulties remembering personal information such as own address or telephone number
- Issues with simple arithmetic

Stage 6: Severe decline

- Personality becomes altered
- Trouble remembering those close to the patient
- May wander or become lost
- Increased suspiciousness and delusions
- Extra help required for activities of daily living such as help with the bathroom and dressing properly
- May have major changes in sleep patterns

Stage 7: Very severe decline

- Loss of ability to interact with the environment
- May have decreased control of muscles

**Stages are defined by the Alzheimer's Association*

6. Are you the *primary* caretaker for the patient? Yes No

If YES, do you have help?

- A home aide Another family member
- The patient is in a care facility, but I also consider myself to be a primary caregiver
- Other: _____

If NO, who is the primary caretaker?

- Patient's child Patient's spouse

- Nursing Home/Memory care facility/Hospital/Hospice Home aide
Other: _____

7. If the patient **does not live with you**, how often do you visit, on average?

- 5-7 times a week 2-4 times a week
Once a week 1-2 times per month
Once every 3 months Once every six months or less

8. If the patient **does not live with you**, how often do you speak on the phone with him/her, on average?

- 7+ times a week 5-7 times a week
2-4 times a week Once a week
1-2 times per month Once every 3 months
Once every six months or less
Patient can no longer speak on the phone

9. Are you familiar with the practice of “therapeutic lying,” fibbing to avoid agitating the patient with a painful line of conversation?

- Yes No

10. At what stage in the disease did you begin noticing communication problems with the patient? Were the issues involve receiving information from the patient, expressing information to the patient, or both?

11. Please describe any specific techniques that you use to improve communication between yourself and the patient? (i.e., Diverting attention away from agitating subjects)

Appendix B: Focus Group Discussion Form

Alzheimer's Disease Caregiver Focus Group			
1	Date of FGD	□ □ . □ □ □ . □ □	DD-MMM-20YY
2	Time of FGD	□ □ : □ □	HH:MM
3	Length of FGD	□ □ : □ □	HH:MM
4	Recorder number	□ □	
Intro	<p>Intro:</p> <p>Hello. My name is _____ and I am a Master's candidate and the City University of New York Graduate Center. Today we would like to have a conversation with you about the role of therapeutic lying in care giving for those affected with Alzheimer's disease. Therapeutic lying is the practice of telling fibs to prevent agitation in patients with degenerative memory loss. I am trying to gain a better insight into the ethical dilemmas surrounding this technique and generally looking at the use of therapeutic lying by non-medical caregivers.</p> <p>Does anyone have any questions?</p> <p>Before we begin, I'd like to go over some rules. First, please turn off your cell phones to avoid interruption. In order to keep track of what people are saying, remember that there should be one person talking at a time. Please do not interrupt someone while they are talking. Also, everything you said today will be audio recorded and kept completely confidential. I ask that you do not repeat what you hear in this room today, and I will de-indentify this record so anything you say is not linked to your name. I will summarize the things you tell us and combine it with other focus groups we are giving. One of my jobs as the moderator is to make sure we discuss all of the issues we planned to discuss. If I ask you questions while you are talking, I'm not being rude; I'm just making sure everyone had a chance to talk and that we discuss all of the issues.</p> <p>Just to get started, let's have everyone share the name you would like us to call you, something about yourself, your relationship to the patient and how long you have been caring for this person.</p>		
Q1	What experience do you have in care giving for an Alzheimer's patient?		

Probes	<ul style="list-style-type: none"> ▫ Have you dealt with multiple family members? ▫ Do you have help with providing care? ▫ Do you actively search for information on Alzheimer's care giving?
Q2	Have you heard of therapeutic lying?
Probes	<ul style="list-style-type: none"> ▫ Do you understand why people may lie to Alzheimer's patients this way? ▫ Do you have any experience with it? ▫ Where did you hear about it and in what context? ▫ Do you do things similar to this?
Q3	Under what circumstances would you consider telling a fib to a patient?
Probes	<ul style="list-style-type: none"> ▫ What factors constitute this behavior? ▫ What are the risks/benefits?
Q4	At what stage in the illness did you begin/would you begin fibbing to the patient to avoid agitation?
Probes	<ul style="list-style-type: none"> ▫ Why? What would trigger you to incorporate this into your care giving? ▫ Did you find it difficult to use this technique? Why?
Q5	What is your biggest concern about withholding information from the patient?
Probes	<ul style="list-style-type: none"> ▫ Have you considered lying to the patient? ▫ What made you reluctant to tell the lie? <p>Do you think it is wrong for a caregiver to lie to an Alzheimer's patient in order to spare them the anguish of hearing the truth? Why?</p>

Q6	When the patient becomes confused and says things that are untrue, do you typically correct him/her? Do you respond as if you are accepting the patient's reality?
Probes	<ul style="list-style-type: none"> ▫ When you offer corrections, how does the scenario typically play out? How do you feel about doing so? ▫ How do you feel about letting the patient live in his/her world?
Q7	What is your opinion on the use of therapeutic lying by medical professionals?
Probes	<ul style="list-style-type: none"> ▫ Should this be reserved for medical professionals, non-medical caregivers, or both? Why? ▫ Would you/do you encourage any medical aides to incorporate therapeutic lying into their care giving? ▫ Is there a major difference between a familial caregiver or a medical professional using this technique? ▫ Do you feel better about fibbing when it is described with the medical term, "therapeutic lying"?

Appendix C1: Focus Group 01

Transcript

Focus Group 01

December 07, 2014

Facilitator: Dina Green

Person	Discussion
Dina, PI	Ok. Hello, my name is Dina, I'm a Masters candidate at the City University of New York Graduate Center. Today we would like to have a conversation with you about the role of therapeutic lying for caregiving, in those affected with Alzheimer's disease. Therapeutic lying is the practice of telling fibs to prevent agitation in patients with degenerative memory loss. I am trying to gain a better insight into the ethical dilemmas surrounding the technique and generally looking at the use of therapeutic lying by the non-medical caregivers. Does anybody have any questions?
Male	No
Female	No
PI	Before we begin, I'd like to go over some rules. First, please turn off your cell phones to avoid interruption. In order to keep track of what people are saying, remember, we should be one person talking at a time. Please do not interrupt someone while they are talking. Also, everything you say will be audio recorded and kept completely confidential. I ask that you do not repeat what you hear in this room today, and I will de-identify this recording so that anything you say is not linked to your name. I will summarize the things you tell us and combine it with other focus groups and interviews we are giving. One of my jobs as the moderator is to make sure we discuss all of the issues here as planned. If I ask you questions while we are talking, I am not being rude, I am just making sure everyone has a chance to talk and that we discuss all of the issue. Let's get started, so let's have everyone share a name you'd like for us to call you, um, anything other than your actual name. It could be Mr. Whatever, anything, or something about yourself... it could be something related to the patient and how long you've been caring for this person. If you could repeat – I know that we discussed it for the demographic survey, but if you could each just repeat that information for the recording I would greatly appreciate it.
Male	I, um, was between, um, 1 and 3 years.
PI	Ok. And it was your mother, right?
Male	Yes.
PI	Ok, and female -
Female	With my mother, and it was between 3 years and 5 years.
PI	Ok, thank you. So can you each speak to what experience do you have caring for the Alzheimer's patient; have you dealt with multiple family members; do you have help providing the care; do you actively search for extra information on Alzheimer's caregiving?
Male	I um, my mother is now in a facility which caters to people who have memory loss

	and she's been there for probably 9 months. And prior to that it would be my sibling who was assisting her and the disease progressed. My own involvement was living from a distance, about 12-13 hundred miles away. So the frequent phone calls and infrequent visits I would be making to NY to see her. We had a – recognizing the steady scope of the disease was on the telephone.
PI	Um can does would anyone else like to speak to any of those points
Female	So the question was what was the - my involvement?
PI	Mhmm.
Female	I, because I lived in another state, and my mom literally lived with my brother and his wife and their 2 children. I was able to visit them about once a month and what I did was, I would relieve the family of normal everyday duties. I would take mom out, she loved to go to the dollar store. I would clean her room, I would do the wash, I would I would clean the house. I would let the – my sister in law and her kids have the day off, and I was able to observe mom by myself, and then I would, I would ask my brother questions about, well, 'this and this, oh she's doing that' – The only way I knew how to contribute to the caregiving, because I didn't live close enough to have daily, doings with her
PI	-Yeah of course-
Female	And I know it gave my brother and his family a reprieve, and I was able to spend time with my mom myself.
PI	Of course, no, that's wonderful. Ok, I'm going to move on to the next question. Thank you very much for sharing. Now, getting on to the therapeutic lying, have you heard of therapeutic lying? And can you speak to the context in which you've heard of it, and do you understand why people may lie to Alzheimer's patients in this way? Do you have any experience with it; where did you hear about it and in what context; and do you think similar to this?
Male	Well, I've never heard of the term itself, but I understand what it is. Like if I heard it in the clinical terms. You know I understand it in nonclinical terms.
PI	Mhmm
Male	But yes, I do understand that you need to lie to the person because you have to minimize the – you have to diffuse certain situations and anxieties, and really not cause any friction in whatever communication ability you have with the afflicted person. So I understand it is necessary to maintain calm.
PI	Mhmm
Female	I never considered it lying interestingly enough, and it was clear to me at the very beginning, that when I noticed behavioral – like she just said that and now she's saying it over again; she just asked that, now she's asking again, and if you tried to correct her she'd go, "You're wrong, I never said that, I didn't do that." And it was clearly just a personality change that you just couldn't confirm. So I didn't really consider it the term lying, even though it is. I just thought it was easier to agree with her and then try and change the subject. But it is. Therapeutic lying is definitely what it was. And without question it made life easier; that was the bottom line.
PI	Mhmm, Yeah. So kind of playing off of that, under what circumstances would you consider telling a fib to a patient? What factors contribute/constitute this behavior, and what do you

	find the risks and benefits are of this technique?
Male	Well, I'm not sure what the risks are, but the benefits are not getting the patient agitated, and not causing grief and such unto the patient for no reason. So whatever you need to smooth things and to make things manageable, that would be the case. As far as the downside, you know the downside of knowing that you're not telling the truth and you're giving someone false information. So that, the kneejerk reaction, is not a pleasant one that you need to do, but it's quite necessary in order to keep you know stability, in the relationship, in communication. So that's the downside, the guilt of lying or whatever, but you know, you have to do what you have to do.
PI	Mhmm, mhmm.
Female	I learned early on there wasn't any risk. It was just do that to make the end result happen. If you needed her to get in the car because you were going to dinner somewhere, and she didn't want to go, or she didn't want to get dressed, or she didn't anything, you just finally told her anything to get her in the car! And so after a while you knew that she wasn't going to remember the argument, and it was clear to just go ahead and try to do whatever you could. That's about it.
PI	Mhmm. At what stage of the illness did you begin or would you begin fibbing to the patient to avoid agitation? Some follows up to that are why, what would trigger you to incorporate this into your caregiving, did you find it difficult to use this technique, and why? If you could focus on if you find it difficult at any point to use this technique, or I feel like we've touched on a number of the other points, but if you could speak to those that would be wonderful.
Male	Well, yeah, you know I didn't want to lie, I wanted to tell the truth, but I wanted my mom to snap out of it, but that's not a realistic expectation in hindsight, and you know you want to be on the up and up, and be truthful and whatnot, but it doesn't make a difference because you have to look at the outcome and you have to look at the what ifs. And if it's something that's going to agitate you know you can't do that. And to appease the person you'd have to lie. And you know we call that a white lie. But, you know, it's still bending the truth. At what stage, I don't know. That's um, hard to say what stage. But-
PI	If you don't know that's perfectly fine.
Male	-Yeah I don't know specifically, I can't pinpoint, is it a year ago, or uh what stage... More notably, just a lack of bringing up certain topics. That would be more constructive to maintain harmony.
PI	Mhmm
Male	Staying away from certain topics, which I know may cause, you know, an excitable level with my mom.
PI	Mhmm, yeah. Do you have anything else to add at all, anyone?
Female	You know, for me, I was thinking, I did research when my brother told me that mom was losing her memory, is how he put it, and then I would visit her and she would be better, she would remember things with me, and my brother would say, 'Well, she - I was asking her about that and she didn't remember anything last week! And now you come to visit her and suddenly she's talking about it.' And I found that very interesting and I started doing research on Alzheimer's and how

	different parts of the brain are working, and if there's any new - oh what's the word -
Male	Stimulus?
Female	-yeah, a new stimulus, like me coming to visit her once a month, it made different parts of your brain work. You know, I started doing research early on, and I had a different knowledge about it. My brother did not, he didn't want to, he did not do research, he just wanted it to go away and it did not. So you know the family impact on it is interesting, but I noticed early on that telling her what she wanted to hear was the answer for me. So stage 2, stage 3, just to keep peace in the family.
PI	Yeah. Did you find though that when you first started having to do this that this was difficult for you to do though? Even though it, I guess, even though, for both of you, even though it presented a more peaceful environment, but actually having to use that technique of saying something that wasn't truthful, was that part difficult for you? Even though you knew it would or hoped that it would create a more peaceful environment? Do you understand what I'm saying?
Male	Yeah. At the beginning, you know, it is difficult because you have to fake it – you're not used to doing it. And after a while it just becomes the norm. You do something for a long enough time, it just becomes the norm. You don't think about it, you just do it. And when you start doing it out of necessity and regularly.
PI	Mhmm, so -
Female	You know, you know, you love your parent. I, I –(starts crying) you love them so much, that you don't want to hurt them-
PI	It's okay.
Female	But you know that what you're doing is for the better. So it is a shame, but it is true that after you do it enough it just becomes the right things to do because you don't want them to have any pain or any confusion. And it was the confusion that was painful. The 'I don't understand why you keep asking me this.' And it was painful, and you just want her life to be better. Yes it was hard, but it did get easier. That's the weird thing.
PI	Thank you. A couple more questions, just a two or three more questions. What is your biggest concern about withholding – if you had any concerns, what was your biggest concern about withholding any information from the patient? And have you considered lying to the patient? What made it - It's playing off the previous question, if anything, what made you reluctant to withhold or not be as truthful with the patient? And if there is nothing that is completely fine, just say so. And do you think that it is wrong for a caregiver to do this? Do you think it is right for a caregiver to do this – I know that you've both been playing into this question already – in order to spare them the anguish of hearing something/the truth that's more painful and why.
Male	My opinion – you know it it's-
PI	It's the same thing
Male	It's about saving discourse, There's no one moment, even if that patient is going to forget about it, why must the person be in that anguish for one moment? Mental anguish? So avoid it. Even for that moment, if their life consists of just living in that moment, then make that moment the best it can be.

PI	Mhmm, yeah.
Female	Yes.
Male	So that's just doing what it is. Is it wrong, no, I don't believe so. I don't believe so. I think you have to do it for the sake of the person that you love! You have to do that. You have to spare the anxiety – and for her any pain. If you can minimize that, so you do all that you have to do to do that. You do. And if it's only words that will make that difference, then you use them.
PI	Does it -
Female	I think it's true. And I found the term “therapeutic lying” to be so interesting because that's exactly what it is!
Male	Yes, exactly!
PI	No, please, please speak to how you feel about the term and everything. That's what I'm looking at also. I, you know, there is the use of even just an established term, versus people just hearing about subconsciously using, you know, this technique. If you could speak more to that it would be wonderful. I just have two questions left, and the last one is very, very quick. But if you could speak more to that, that would be wonderful; if not we can definitely move on.
Male	How - about, the lying part to me?
PI	Yeah, about that, even just the term.
Male	Well, you know, I've never heard the term before, but that's pretty accurate for that it is. Its therapeutic lying. I wouldn't say it's lying without guilt, because you're aware. The person who's lying is aware that they are lying. You know you can't avoid that.
Female	But lying is a negative term! And you, and it's your loved ones. It's truly an interesting thing-
Male	It's better than the heartbreak, it's – you're saying things that may not be accurate, in order to manipulate them into doing something which will be better for themselves.
Female	“Therapeutic” means healthy and good and getting better, and “lying” means “Oh my gosh! This is terrible.” (laughs)
Male	So there's an oxymoron? Ya know.
PI	That's why this is a bioethical issue. (laughs)
Female	It is correct. And it gets your attention because it is what you're doing. And
Male	Yeah, and you still have to do it. There's no doubt, you know. Anybody in this position, anybody with any exposure to this, knows that there is no question, you have to do it.
Female	I don't even think it's a question.
Male	You have to employ the technique, it's absolutely impossible to avoid it.
Female	It is.
PI	Yeah. So just, uh, when the patient becomes confused or says that aren't true, do you typically, correct him or her, do you respond as if you are accepting the patient's reality? When you offer corrections how does the scenario typically play out? How do you feel about doing so, and how do you feel about letting the patient live in his or her own world? This question's really more about how it makes you feel, rather than what you're doing for the actual patient, if that makes any sense.
Male	Yeah, no I understand what you're saying. Yeah, sometimes I have to think for

	<p>myself, personally, something I'll say you know...my mother may forget I'm living in Florida, so I'll remind her that I'm living in Florida. Is it necessary to say that? No. But I'll try to maintain some sort of a little bit of reality so that she can live, and keep maybe, a toe in those waters of reality. So she'll say, 'Oh. That's right, you love Florida, and you love the weather', and so forth. So I pick and choose when to correct a flaw in the, in her reality.</p>
Female	<p>I disagree with that. I want to be in her world. I want her to be happy where she is. I'll bring up her past; I'll ask her if she remembers her boyfriend – I don't correct her. I don't correct her at all. I want to be where she is because I know if I get on that road of "don't you remember that green house that we lived in that you loved with the flowers?" and she doesn't even remember it, then that could start a negative process, and that's not a good thing. So I'm just there for the moment if she is too.</p>
Male	<p>Right, but then you think, well then if my mother says, 'my address is in Brooklyn, right?' and then the question is, well, do I just say 'Right.' And appease her, or do I say, 'Queens. You live in Queens.' So that's a process. Each particular sentence or item has to be dealt with in and of itself.</p>
PI	<p>Mhmm. Thank you – and one last question. What is your opinion on the use of therapeutic lying by medical professionals, specifically? I'm going to read you a couple of probes, if you could speak to any one of them:</p> <ul style="list-style-type: none"> -Should this be reserved for medical professionals, non-medical caregivers, or both and why? -Would you or do you encourage a medical aide to incorporate therapeutic lying into their caregiving? -Is there a difference between a familial caregiver or a medical caregiver using this technique? -And do you feel better about fibbing when it is described with the medical term, therapeutic lying?
Male	<p>Well, when you say therapeutic lying it's like cleaning up what it really is. You know, it's putting lipstick on a pig. And that's still lying. Then your question is, which is a great question, do you have nurses/aides besides the actual certified medical people, and the family?</p> <p>I think for the betterment of the patient, it's okay. For the betterment of the patient, at the end of the day I think that's what really counts. And I think the family has to be aware of the condition of the patient to make sure that they are getting the right care. I wish the whole thing wasn't necessary, I wish we didn't have to lie, I wish it didn't exist. But it's a reality, and just like the lines are necessary, you know. If you have to lie for the patient's betterment, then you have to do it. You have to do it. I mean because at the end of the day that's what counts – that you're doing it for the betterment of the patient.</p>
PI	<p>Yeah.</p>
Female	<p>I think that family, doing what they're doing is okay, and certainly the right thing to do because there is a different background with them. The medical professionals, I think it would actually be easier for them to carry on the therapeutic lying because they don't know anything about the patient. So if the patient says 'where am I? Am I in a hotel?' They can just say 'yes, it's a hotel.' Initially when you asked the</p>

	question I didn't want to say yes, I didn't want people lying to my mom, but then I'm thinking yeah! They have to.
Male	That's a great example also, "where am I in a hospital? In a hotel?" that's a great example.
Female	And it's because there, you know again, I think it's important for the happiness of the patient to go with the flow of her brain. That's why I don't want to correct her, I don't want to remove her from that.
Male	And if it will facilitate better care
Female	Right
Male	For my mother then by all means
Female	True
Male	But, likewise I don't like the idea of anyone lying to my mom, but that's a protective, a family protective thing – protecting, but like I said at the end of the day, everything is about the quality of life and quality of for care of the patient.
Female	Yeah, it's true.
PI	Ok, so those are all of my questions. Does anybody have any questions or comments before I close the recording?
Female	No, I'm so happy that you're doing this, because knowledge is power and this is really important to get people's opinions of things because you're kind of lost after.
PI	Thank you, thank you both so much again.
Male	Uhuh.
PI	I'm going to close the recording right now.

Appendix C2: Focus Group 02

Transcript

Focus Group 02

December 07, 2014

Facilitator: Dina Green

Person	Discussion
PI	Hello, my name is Dina, I'm a master's candidate at the City University of New York Graduate Center. Today we would like to have a conversation with you about the role of therapeutic lying in caregiving for those affected with Alzheimer's disease. Therapeutic lying is the act of telling fib to prevent agitation in patients with degenerative memory loss. I'm trying to gain a better insight into the ethical dilemmas surrounding this technique. I'm generally looking at the use of therapeutic lying by non-medical caregivers. Does anyone have any questions?
Jane	No.
PI	Before we begin, I'd like to go over some rules. Please first turn off your cellphones, as to avoid interruption. In order to keep track of what people are saying, remember that there should be one person talking at a time. Please do not interrupt someone while they are talking. Also, everything you said today will be audio recorded and kept completely confidential. I ask that you do not repeat what you hear in this room today, and I will de-identify this recording so that anything you say is not linked to your name. I will summarize the findings you tell us and combine it with other focus groups we are giving. One of my jobs as the moderator is to make sure we discuss all of the issues we plan to discuss. If I ask you questions while you are talking, I am not being rude, I am just making sure everyone has a chance to talk and that we are discussing all of the issues. Just to get started, let's have everyone share the name you would like us to call you; so think about yourself, your relationship to the patient, and how long you've been caring for this person.
Jane	I'll go first. My name is Jane, and I have been caring for my mother who has had Alzheimer's for, we realize now it's more than just the 3 years that we recognized it. She is currently in a memory care facility.
PI	Thank you, Jane.
Fred	My name's Fred. We've been working, caring, for my mother in law for approximately the same 3 year period, and she's also in a facility.
PI	What experience – so that's the first question – what experience do you have in caregiving for an Alzheimer's patient? And some points here if you could touch on: how have you dealt with multiple family members? Do you have help providing care? And do you actively search for information on Alzheimer's caregiving?
Jane	When I was very young we had my grandmother who has Alzheimer's, advanced Alzheimer's by the time I was born, so I grew up in a home where I knew what the later stages were like, but I never realized until my own mother started developing the symptoms what it would be like, and what was entailed in the person who was

	declining. I absolutely went to the Alzheimer's association. I called asking for help with the referrals for in home care which didn't work out. I bought books on it which I read. And my sister and I eventually went to look at facilities that might be better suited for her because it was a more social atmosphere.
Fred	I've been primarily in a supportive role. Helping – grappling – helping with doing some research, helping with providing of meals, helping with going to facilities when we ultimately found them, but it's been primarily in a supportive role of my spouse.
PI	Thank you. So, just to get to the topic of therapeutic lying, how have you heard of/have you ever heard of therapeutic lying? Do you-
Jane	Yes, yes. I'd heard of it and it was actually... It was interesting to read about it in a book because you really want to work with the patient as well as you can to get them calm and just get through the day, and then when you read about it then you realize that people are doing this and it's really a great thing. It also, it happens to be a wonderful family support group in the facility where my mother is, and we actually discussed this. It was at my first family support group meeting, and it was really very, very helpful because the first time we really ever had to use a therapeutic lie was when trying to leave when we went to visit. And it was very, very hard to get out, so you have to make something up to try to separate. And I found out that everybody does that, and it's very, very hard to do, but people who have relatives, who've been doing this for a while, were encouraging me because it was so necessary.
Fred	In my case, I became familiar with the term in my interactions with family members, and also professionals, as we tried to each transition. And what we found was when there were interactions with other residents where my mother in law lives, there has been a lot of dialogue about it and a lot of discussion about how to use it, the best place to use it, and that's how I came to hear about it.
PI	So it's really – you both mainly learned about it through research and the facility. Correct?
Jane	Yes.
Fred	Yes.
PI	Did you/ were you / before you learned about this, were you doing similar things before?
Fred	Doing what? Could you repeat that please?
PI	Were you using similar techniques without the knowledge of this exact technique before then?
Jane	Well I really tried to avoid it. I didn't really know what I was supposed to be doing, so it was very difficult. And I guess, you know, you try to stretch the truth a little bit so that it just transitions, but I didn't realize how necessary it was, especially as the disease progressed, to... just it was really, I realized it was for my mother's own good, because she was no longer dealing with realistic situations or consequences. So it was really very important.
PI	So for the third question, under what circumstances would you consider telling a fib to a patient? What factors constitute this behavior from you and what do you feel the risks and benefits are?
Jane	So, the circumstances for me would be keeping her calm, keeping her from being

	<p>upset, if I could take something that really didn't have a negative consequence to anyone. So that's really the most important thing because once she gets agitated it's very hard to calm her down, and there is really no reason to upset her if I can avoid it.</p> <p>And I'm sorry, what was the second part?</p>
PI	What do you feel the risks and benefits are?
Jane	Well..
PI	If any.
Jane	<p>Well fortunately or unfortunately there's very little risk of her remembering that I said it because at this point she doesn't – she has almost no short term memory. And so as the disease progresses and you need to do it more, they actually don't remember what you told them so it's really just a very temporary fix. And as for a reward – it's very hard to call it a reward, but at least you know you're not making their life any more difficult by saying something that would be agitating them.</p>
PI	Mhmm.
Fred	<p>I mean, my experiences were very similar as Jane. There typically you would use things in transition periods when you were trying to either work your way through coming in to visit a person, whether it's in the home or in the facility, activities while you're there, and then interactions with other people, as well as then your ultimate exit. And what's said previously, is that it's all about managing the agitation factor. You know, you have a person who is struggling with their own inability to function, and not really realizing it, and in denial of what's happening, so they get frustrated, and you have to manage that, and often the best way to do it is through, as you called it, the fib, and I think it's appropriate to use it. And I don't think there's that many negative ramifications because it's not being ever done in a malicious manner, it's only being done when you're trying to transition something, when you're trying to help with a meal, when you're trying to get things cleaned up, when you're trying to make sure the support system is all in place. You know in terms of people having food and shelter, and then you have to then leave at some point. So I think that it's all very, very important in the transition, with not a lot of downside.</p>
PI	Mhmm, mhmm.
Jane	And I wanted to add, if I could,
PI	Yeah?
Jane	<p>That very often the fib is one of omission. It's That you're not correcting the person. So if my mother thinks she is still in the house that she grew up in, I'm not correcting her if that is comforting to her in that moment. So it's not only making something up that I consider part of this, it's also, it's not correcting her if she's comfortable in believing something at the time and it doesn't have any downside.</p>
PI	<p>Yeah. I'm also going to ask you to speak to that in a couple minutes as well. At what stage of the illness did you begin or would you begin fibbing to the patient to avoid agitation? Why so? What would trigger you to incorporate this into your caregiving? Really speaking more to how it affects you than the patient, did you find it difficult to use this technique and why?</p>
Jane	<p>I realize now I probably should have started it earlier because I didn't really how impaired she was and then once I didn't, I didn't. I just didn't know that changing</p>

	<p>things slightly would make it difficult for her and for me. I don't know the exact stage but it was probably in 5 and it mostly started when she really couldn't get through her activities of daily living anymore and she needed help and didn't want it. And I needed to lead her into a facility without her being – I needed to get her in. And I think that was the first time we really didn't tell her right up front exactly how long – where she was going, how long she was going, and it was very, very, very difficult. I think that for her it was difficult for much less time. We still live with it, but it was again, because of the nature of the disease, it's easier for patients to get over it, because they don't retain memory of it.</p>
Fred	<p>Yeah – for me, I think where I've seen it used the most is in the ultimate transition – that when somebody is moved out of their home. When they were in the home, you know in my experience, it was more a sense of major denial on their part. Not recognizing that the food was prepared for them, not recognizing that they weren't shopping, not recognizing that they weren't driving, et cetera. So there would be the only time you know you would ever have to make up something would be, look, actually a lot of it was – 'You know I have to go I have to leave.' Once they were in the facility a lot of it was to facilitate the process. Because what we found is that there's still a lot of times when she thinks she's still in her apartment, she thinks she's in the lobby of her apartment, and you know for my experience it's been at that time that you have to transition things. Whether it's from a meal, whether it's an exit, whether it's into another activity, it's whatever's going to make it easy. And I think that's another thing. None of it is malicious; it's all to ease things in because it works for everybody. It works for the caregiver, and it works for the individual, who, again, is living in a world where they're in a fog. They think they know what's going on and sometimes they know they don't know what's going on, so you have to make it easier for them.</p>
PI	<p>What is your biggest concern about withholding information from the patient? Have you considered lying to the patient? What made you reluctant to tell the lie? Do you think it's wrong for a caregiver to lie to an Alzheimer's patient to spare them the anguish of hearing the truth? And why or why not.</p>
Fred	<p>Ya know, it's... Let me go back to something that Jane said earlier, that it's in the context of omission. I think that there's, as it's used in my experience, as it's used there, it's only used in a transition period. I don't view it as the fib to tell somebody that they're in their own apartment, or to agree with them when they think that they are in the apartment. To me there's no downside to it because you're only using it in specific contexts. You know, which is, how are we going to make things easier for the individual. And in our care of using it, it's not to pressure them into anything; it's not used to force them anywhere. And again, I keep using the term transition, but it's the transitional activity period, from basic conversation to eating, to activities, to then leaving. Again, I don't feel badly for doing it because I know it's all in a very closed context.</p>
Jane	<p>I think that when I first realized that I really had to – that I couldn't give my mother what she needed and also be totally honest – that's a very hard thing. And it was really survival for both of us. And it comes with a lot of guilt. Until you realize that it really is better for her. And it was a very interesting thing that happened, again in the family support group from the facility where my mother is.</p>

	<p>There was a family who had just put their- just registered their mother in this place, and they were beside themselves because they said they can't leave, and the mother is saying, 'Don't leave me here, don't leave me here!' And they said, 'how do you get out?' And everyone in the room said you have to lie to them. You say you're going to the bathroom; you'll be right back in. You have to get your purse. And the girl was irate. She said, 'I will never say that! I will never lie to my mother.' And it was a very interesting thing, because at that point I had just started having to do it myself. And I thought to myself, you know, give it a few weeks, because you won't be able to survive. And it isn't good for the patient not to do it, because it's too agitating for them. So yeah, I think that it comes easier as you realize that it really is for their benefit. And you come up with the lines that you know work. And it's not really as simple as it sounds, but it is a technique that absolutely helps them, as well as the caregiver.</p>
PI	<p>Thank you. I just have a couple more questions left. When the patient becomes confused and says things that are clearly untrue, do you typically correct him or her? And I know you spoke to this a little bit before, but do you respond as if you're accepting the patient's reality? And just to give you some ideas for points to touch on:</p> <p>When you offer corrections how does the scenario typically play out? How do you feel about doing so and how do you feel about letting the patient live in his or her own world?</p>
Jane	<p>That's a great question, and we actually touched on that earlier. I don't correct her unless I need to, and would you want an example? Would that be helpful?</p>
PI	<p>Yes, please. Yes.</p>
Jane	<p>You know, if she tells that, you know, that she thinks that she is living somewhere else, if she tells me that she's been living there for a week, instead of the six months that it really is, I would never correct that because that's fine that she thinks that. When she tells me that – when it's something that agitates her, then I correct her. And that's the only time that I do because then there is a reason to. If she tells me that all the people sitting around her are in her apartment and we're not inside it, and it's very important to her to get them out immediately, then I correct it, because it could create a really bad situation for her as well as the other residents. So again, that would be the only time I would correct her. She has told me that she was married to one of the men who was there, all kind of things and I say 'Oh, that's nice.' It really doesn't serve a purpose to correct her. The truth is, she's happy in this, in this environment, in her own world, that's great because, you know, that's what I want. I want her to be happy with whatever she can be at this point.</p>
Fred	<p>So, with my experience, I put it into two different tracks. The most recent track, which is once my mother in law was in a residence that really catered to her needs and facilitates a much better existence for her, with our support there as well, I find I never correct her on certain things, other than if it's really – the agitation things – but I really haven't experienced that much and a lot of times I'll just ignore that if I see that we can just transition out of that. You know, just transition out of that. Earlier, I found when she was still living at home, there was more correcting going on, especially when it came to food, when it came to, you know preparation of</p>

	<p>food, paying bills, driving, and things like that, because that was more in the context of thinking that a light would go off for her, that, ‘Wow, I really do need help.’ So there I think that we corrected more because we were trying to let her know what her reality was. But since she’s been in the residence I don’t find the need to really correct because, again, unless she’s agitated, but I haven’t found that that much.</p>
PI	<p>Thank you. I have one more topic to cover. What is your opinion on the use of therapeutic lying by medical professionals specifically? So you as the non-medical professional caregivers, I’m asking your opinion on medical professionals. And some follow-ups are: should this technique of therapeutic lying be reserved for medical professionals, non-medical caregivers, or both and why? Would you and do you encourage any medical aides to incorporate therapeutic lying into their caregiving? Is there a major difference between a familial caregiver or a medical professional using this technique? And do you feel better about fibbing when it’s described with the medical term therapeutic lying or therapeutic fibbing? Just having that established construct there, as opposed to just being told that, you know, go out there and you know, you shouldn’t necessarily be truthful. And I’m happy to repeat anything.</p>
Jane	<p>(laughing) Okay.</p>
Fred	<p>Yeah that was a, a laundry list. I’ll go first, that’s fine. So, differentiating between medical professionals and residents and us. I have very mixed feelings about the medical professionals, or actually, for the professional caregiver, because I know why we do it. I would – You know when somebody else is doing it I guess I need to know why they’re doing it and what the context is of their doing it because I know what our intentions are but I’m not quite sure what others’ intentions are, so I would want to reserve judgment on that. The only thing that I would say that may be okay would be when you have certain patients, in fact, like my mother in law, who has never been or ever wanted any medication, and isn’t aware that she’s on a very light medication to help her with her agitation. That kind of thing, I don’t know, since it’s a manageable dose, and when family is helping manage that process with the intentions, you know, of only dealing with slight cases of agitation, I think then it’s okay for the professionals to massage the process on how they’re going to get that patient to take their medication. But other than that I have very mixed feelings, because although you want to hope that the intent of the professional caregiver, whether medical professional, or an agency type caregiver, what their intentions are, I can’t manage that process, and that concerns me a little bit. What were the other – you had some other..</p>
PI	<p>Oh, just should this technique be used by both, or just one or the other, and what is the main difference, do you think, between/ or is there a major difference between a familial caregiver or a medical caregiver using the technique?</p>
Fred	<p>Yeah, I mean I kind of think I covered that-</p>
PI	<p>Yeah-</p>
Fred	<p>Saying that I don’t know what their intentions are, so that’s what – you know it’s scary when that family member isn’t living with you; when you can’t control and</p>

	see really everything that's going on in their day, and this individual is older, and you know that they're frail, and you know that they're frail mentally as well, and physically, I, again I have mixed feelings. I'm not sure I would want them using it without going over parameters, or maybe setting parameters for how and when it's going to be used.
PI	I know that you gave me an example, right; if either one of you could give me another example of the medication and everything. I guess another example of what your fear would be; of what would happen.
Jane	I can give you an example.
PI	Yes. Thank you.
Jane	I don't feel exactly the same way, because I think if it's a physician who only sees the patient only once in a while, they have no idea what are the triggers, or why – I don't think the therapeutic fib really needs to be used that much by a physician, but by a caretaker, we have actually instructed some of the aides who work with my mother, what they should say, when my mother brings something up such as where she lives. You know, 'Where am I?' So I think that it is okay if it's people who know her, know her personality, know how she's thinking, and know what our wishes are. So I agree with what Fred said, about that you need to have some parameters. An example – did you ask an example where it would be – ?
PI	What your concern would be; an example of where you think that this could be misused.
Jane	Well my concern, I actually can tell you, I was with her when she had to go into the physician at the facility and they wanted to give her a flu shot. And she didn't want to get the flu shot at that time. She thought it was nighttime, whatever the reason, she didn't want to get it, and he said – he made something up that he was going to – he said to her, 'Okay, then you don't have to get it.' And then he said to me, 'We'll give it to her when she's sleeping.' So she heard – you know with her memory as bad as it is, she heard him say one thing to her, and then immediately following, but with the truth, to me, and that was a really bad thing. So again, if it's not someone who is sensitive to that person's needs, and really... it depends who the person is. Usually the aides are very, very caring and get to know the person. But I don't believe that a doctor should use the therapeutic fib, unless it's just to calm the person that everything's okay. The "everything's okay" thing I think is good.
PI	Those are all the questions that I have at the moment. Do you have anything that you would like to add at all, either one of you, before I close the recording?
Jane	No, the one thing I would like to add is that I think it's great that you're doing this because not enough people talk about it, and I know that Alzheimer's is not only rampant now, but growing and there isn't enough emphasis on it. I know that the Alzheimer's Association does a great job, because they are a resource that I personally have used, but support groups are very, very important, and everyone should be encouraged to go.
Fred	No, I just want to thank you for doing this too. It's a great topic, it's an important topic, and it should be discussed more.
PI	Okay. Thank you very much. I'm going to shut off the recording now.

Appendix C3: Focus Group 03

Transcript

Focus Group 03

December 10, 2014

Facilitator: Dina Green

Person	Discussion
PI	Hello, my name is Dina. I am a master's candidate at the City University of New York Graduate Center. Today we would like to have a conversation with you about the role of therapeutic lying in caregiving for those affected with Alzheimer's disease. Therapeutic lying is the process of telling fibs to prevent agitation in patients with degenerative memory loss. I am trying to gain a better insight into the ethical dilemmas surrounding this technique, and generally looking at the use of lying by non-medical caregivers. Does anyone have any questions?
He	No.
She	No.
PI	Before we begin I'd like to go over so rules. First, turn off your cell phones to avoid interruption. In order to keep track of what people are saying, there should be one person talking at a time. Please do not interrupt someone while they are talking. Also, everything you say today will be audio recorded and kept completely confidential. I ask that you do not repeat what you hear in this room today and I will de-identify this recording so that anything you say is not linked to your name. I will summarize the things you tell us and combine it with other focus groups we are giving. One of my jobs as moderator is to make sure we discuss all issues as planned to discuss. If I ask you questions while we are talking, I am not being rude, I am just making sure everyone has a chance to talk and that we discuss all of the issues. Just to get started, let's have everyone share the name you would like us to call you, something about yourself, your relationship to the patient, and how long you've been caring for this person.
She	My name is "She". It's my mother that we're talking about. My mother has had Alzheimer's for probably about 6 years and she was living at home, she was living by herself in her apartment, until she became, we thought, a danger to herself. At this point we placed her in an assisted living for memory care.
PI	Thank you.
He	This is "He" speaking. We're talking about my mother in law. She's probably had Alzheimer's for maybe 7, 8, 9 years; it only became obviously to us, at least to me, about 5 years ago. She was being cared for in her home with a lot of assistance from her family, even though she wanted to be independent. When it became impossible for her to be independent any longer, she went into a health related facility, an assisted living that specialized in memory care.

PI	Thank you. What experience do you have in caregiving for an Alzheimer's patient? Some things that you may want to speak to is have you dealt with multiple family members, do you have help providing care which some of you already spoke to, and do you actively search for information on Alzheimer's caregiving?
She	Okay, this is She speaking. My experience has been that I grew up in a house where my grandmother had Alzheimer's, where she lived in almost a vegetative state for many, many years with the Alzheimer's. And I do remember that when she was in declining health, I remember that she was losing her ability to communicate and her speech. My other experience is that I am a speech therapist and I deal with people with neurological conditions and I've taken coursework in dementia.
He	My experience primarily and personally with my wife's mother, and her grandmother, who I took care of on a professional basis to some degree, when she had advanced Alzheimer's Disease, I took care of her in her home, including advanced care that most people would only get in a hospital setting. In addition to that, my previous experience is as a physician of internal medicine. I've cared for many patients, who've had Alzheimer's disease and advised them, and only now that I've experienced it personally do I realize how superficial most physicians' knowledge is on the disease.
PI	Thank you. So onto the next topic, have you heard of therapeutic lying? Some points you may want to touch upon are: do you understand why someone may want to lie to Alzheimer's patients this way? Do you have experience with it? Where did you hear about it and in what context? And do you do things similar to this?
She	Okay, I have heard of it. I use it. It's something that at first I was not comfortable doing, but I think that it was beneficial to my mother. It seemed to calm her down when we could tell her the things that she wanted to hear. We didn't want to upset her when she questioned the deaths of people that had passed away years and years before, including her own parents and grandparents, and I think it's a fantastic tool. It's something that I would never have thought that one would need to use, or that I would be capable of using, but I have found it to be really helpful in dealing with my mother.
He	As for me, in my medical training, in both medical school and internship and residency, we were taught specifically not to lie to patients. We were taught to... that if they said something incorrect, we should correct them – very gently, but nevertheless correct them and move on, and that we should correct them again and again and again. That was the basis of my understanding of the appropriate way to treat them, but it was only late in my career that the concept of therapeutic lying was first introduced to me, and by the time I had to use it personally, I was only moderately comfortable with it. And I found it to be difficult at first, but later got used to the concept, and found that it was invaluable in my caring for my mother in law and invaluable in her comfort and well-being. And I go along with that concept, and do so until today.
PI	Thank you. Under what circumstances would you consider telling a fib to a patient? What

	factors constitute this decision and what do you feel are the risks and benefits, if any, of this behavior?
He	Could you just repeat the first?
PI	Sure. Under what circumstances would you consider telling a fib to the patient or family member? What factors constitute this behavior? And what are the risks or benefits of this technique?
She	Okay, my mother would be agitated. I found that the therapeutic lying calmed her. I find that it's just been an invaluable technique to use because her expectations since the dementia are so base. They're not... she's losing her executive functioning; she's not able to process the emotions and the ability to separate fact and fiction. So using the technique of therapeutic lying seems to ease her into her new state of mind.
He	As for me at this stage I have no difficulty fibbing or lying as long as the goal makes her more comfortable. For a long time now I've figured out her memory is so that she is confused, she doesn't know where she is most of the time, and she doesn't know what's right and what's wrong. And if we insist on going one thing that's right, she's wrong; it just makes her more anxious. And she'll never remember what the right or wrong is anyway, so I think the goal is to make her feel more comfortable rather than make her knowledgeable. And that to me is a big benefit. From a risk point of view, I really don't see the downside of it for her, maybe sometimes for the caregivers, because they feel that they shouldn't lie, and that's something you're taught in childhood, but if you're considering the wellbeing of the patient, at least for me it's the right thing to do.
PI	Thank you. At what stage in the illness did you begin or would you begin fibbing to the patient to avoid agitation? Why? And in other words, what would trigger you to incorporate this into your caregiving? And did you find it difficult to use this technique and why? – which you spoke to a little bit already, but if you had anything to add I would appreciate it.
She	Like at what point?
PI	Right.
She	I could say, when – when she was unable to function independently in her apartment. At first, we were correcting whatever she was saying, but when we saw that she really had no idea of time and of place – she didn't know where she was, she couldn't discern day and night – those were the times that we really started to employ that technique. What was the other part of the question?
PI	Did you find it difficult to use this technique and why?
She	Yes. At first I do because that's not the way I think. I – lying sort of goes against me. So, saying that to her, you know, we would always try to correct her but then we saw that that made her much more agitated, so we started telling her using the therapeutic lying to calm her.
He	I would say, I first started using it when she was confused and disoriented and became agitated during a conversation when what we were saying didn't seem to match up with what she was believing. And lying actually made her more comfortable, and because of that I have no more difficulty continuing it because she's clearly more comfortable, less agitated, and happier when we confirm for her

	that she's really in the state that she thinks she's in rather than reality.
PI	Thank you. What is your biggest concern about possibly withholding information from the patient? Have you considered lying to the patient? What made you reluctant to tell the lie, if at all? And do you think it is wrong for a caregiver to lie to an Alzheimer's patient in order to spare them the anguish of hearing the truth and why? I understand that spoke to almost all of these points already, but if you have anything else to add, please let me know.
She	I don't think there's anything wrong with it as long as it's to the benefit of the person – the patient. I think that when a person becomes agitated about money, about their house, about maybe somebody is sick and they can't do anything – things that they interpret as being out of their control, the therapeutic lying, it makes it easier for them, in that it makes them less agitated, and I think that it's just better for them in general.
He	I think I've answered the question; the only thing I would add is-
PI	Yes-
He	That the problem occurs when there are multiple caregivers and some of the caregivers believe in the therapeutic lying and others don't, and that might temporarily make the patient even more confused, but with these progressions they are really not aware of any inconsistencies between what two caregivers might say.
PI	Thank you. I just have two more things to cover. When the patient becomes confused and says things that are untrue, do you typically correct him or her? Do you respond as if you are accepting the patient's reality? When you offer corrections how does the scenario typically play out? And how do you feel about doing so and how do you feel about the patient living in his or her own world? If you could just elaborate on some of the points that you made earlier, that would be wonderful.
He	I consistently corrected the patient in the early stages of my care for her, until I was introduced to the value of therapeutic lying and then switched over and then I found it to be so much better. So I no longer correct her, except very rarely maybe, when correcting her will help to move whatever activity is going on – if it will help to move it along. Other than that I don't act with surprise to anything that she says. I don't try to laugh at her or to demean her in any way. Whatever she says is worthy of being said and we react to it as if it were true and real even though we know it is not.
She	I was correcting her before she - when she was still living on her own, and I saw she became belligerent, she was being hostile, she became more agitated. It just – it was a bad situation. So learning this technique has made it so much easier. Whatever she says, as long as it's not harmful, or will end up in something harmful to her physically, we let her have her say, we let her think whatever it is that she's thinking about, and she just seems to be much more peaceful and calm when we do that.
PI	Thank you. I have just one more topic to cover; please let me know if you would like me to repeat anything. What is your opinion on the use of therapeutic lying by medical professionals? Should this be reserved for medical professionals, non-medical caregivers, or both and why? Would you or do you encourage any medical aides to incorporate therapeutic lying into caregiving? Is there a major

	difference between a family caregiver or a medical professional using this technique? Ad do you feel better about fibbing when it is described with the medical term “therapeutic lying”?
She	Okay. I don’t like the idea of the medical professionals lying; I wouldn’t want them to lie to me. However, I would – I think that using therapeutic lying when dealing with an Alzheimer’s patient in a significant stage is something that might calm the patient, might put them more at ease. I think that now, after using it and doing it, it might be a good idea when it’s used properly and when it’s monitored.
He	I would say, as a medical professional – a physician – I don’t have difficulty in the lying to the patient, because it usually doesn’t serve too much of a purpose. The visit the physician has with the patient usually is brief, and it’s focused on a specific problem, and the questioning has to be objective questioning, even if the answers aren’t always, and usually the physician can deflect the lying portion of it to the other people around, the family members who are there, perhaps the aides, in order to get the patient to move on to the next subject. Like going to the doctor’s office or to leave the doctor’s office. But the physician himself doesn’t really have to do it in most cases. I think also, the aides shouldn’t go out of their way for their convenience sake to be lying to the patients, but only should be lying to them when it reduces the agitation of the patient, makes them more comfortable, and helps to improve the daily routine, and helps them get to the appointment and to situate the activities of daily living.
PI	Thank you. Also just one thing, if you would feel comfortable answering. Do you feel better about this fibbing technique when it is described with the medical term of therapeutic lying or even therapeutic fibbing? But having an assigned term for it.
She	Do I feel what?
PI	Do you feel better about using the technique is there’s an assigned medical term to it?
She	Well I’m probably going to use it no matter what, but I think it’s good because people are aware of what’s going on, and I think it’s something that may be – when I go to a support group for Alzheimer’s, people are not aware of that term, and there are a lot of people who don’t practice this, and it might be because they’re not aware of it, and maybe if the term was more out there and people knew more about it they might find it helpful.
He	And I’m very happy about using the term; I’m glad it exists because number 1, it helps you to communicate with others if you’re all using the same language, and truthfully, therapeutic lying sounds like some medical term that absolves you of all personal guilt in the lying. And that’s OK because the caregivers have to feel comfortable too, not just the patient.
PI	Okay, great. Thank you very much. Does anyone have any closing comments before I shut off the recording?
She	Not me.
He	No. I’d be happy to answer any other questions you might have.
PI	No, that’s it. I’m going to shut off the recording now. Thank you very much.

Appendix C4: Interview 01

Transcript

Interview 01

December 21, 2014

Facilitator: Dina Green

Person	Discussion
PI	Hello, my name is Dina Green. I am a master's candidate at the City University of New York Graduate Center. Today we would like to have a conversation with you about the role of therapeutic lying in caregiving for those affected with Alzheimer's disease. Therapeutic lying is the process of telling fibs to prevent agitation in patients with degenerative memory loss. I am trying to gain a better insight into the ethical dilemmas surrounding this technique, and generally looking at the use of lying by non-medical caregivers. Do you have any questions?
Mr. Brown	No.
PI	Before we begin, I'd like to go over some rules. Everything you say today will be audio recorded and kept completely confidential. I ask that you do not repeat what you hear in this room today or on the phone today, and I will de-identify this recording so anything you say is not linked to your name. I will summarize the things you tell me and combine it with other focus groups and other interviews that are being given. One of my jobs as the moderator is to make sure we discuss of the issues that were planned to discuss. If I ask you questions while you're talking, I am not being rude, I am just making sure everyone has a chance to talk, and we discuss all of the issues. Just to get started, if you'd please share your name - the name by which you'd like me to call you, something about yourself, your relationship to the patient, how long you've been caring for this person.
Mr. Brown	You will know me as Mr. Brown. I was a caregiver for my mother who had Alzheimer's disease for approximately 20 years. I was her full-time main caregiver for 15+ of those years.
PI	Thank you. So what experience do you have in caregiving for the Alzheimer's patient? Questions you may wish to address are: have you dealt with multiple family members? Did you have help with providing care? And do you actively search for information on Alzheimer's caregiving?
Mr. Brown	Alright, I have to try to remember all those pieces.
PI	I'm happy to repeat whatever.
Mr. Brown	So, did I actively search? Yes, I contacted the Alzheimer's Association early on in my caregiving responsibilities. I accumulated a tremendous amount of knowledge based on their offerings. I did an extensive amount of legal work. I was in their very first caregivers' workshop, which is many, many years ago now. I was part of an Alzheimer's Association sponsored support group for, well, for the length of time I cared for my mother until shortly after her death. I was also part of a support group at a residence [facility name and location redacted], where we actually

	<p>formed our own, so I was part of two support groups for periods of time while my mother was ill.</p> <p>Now what else did you ask me, because I forgot now.</p>
PI	Did you have help providing care?
Mr. Brown	<p>Yes. I had help providing care for almost the entire time. We identified that my mother had a problem, because in the beginning, although I, in the beginning, knew rather immediately that I was dealing with Alzheimer's disease, but until there was an actual diagnosis I didn't say that I was, but I was, I would say 90% certain. And as soon as I realized what I was dealing with I started having someone come into the home immediately. So I would say for the time that I was responsible, 98% of the time, someone was supporting the care that I was delivering.</p>
PI	<p>Thank you. For the second question, have you heard of therapeutic lying? And again, questions you may wish to address: do you understand why people may lie to Alzheimer's patients in this manner? Do you have any experience with it? Where did you hear about it and in what context? And do you do things similar to this? I am happy to repeat anything throughout this discussion.</p>
Mr. Brown	<p>I have never heard of it certainly named the way you have named it before I was in contact with you. That's the first time I would say I have ever heard of it, let's say in clinical terms. I have discussed with others, let's call it "managing emancipations" but not in such straightforward clinical terms. So actually no, I haven't heard of it as a formal let's call it treatment method, because I would consider it a treatment method. Did I do it? Yes, I did it almost from day 1. I can't imagine not doing it. More than therapeutic, I believe that with any dementia patient, particularly an Alzheimer's patient, if you find a method of making the patient feel better, you should use it period.</p>
PI	<p>Moving on, under what circumstances would you consider telling a fib to a patient? What factors constitute this behavior and what do you believe the risks and/or benefits to be, if any?</p>
Mr. Brown	<p>I think that you should use your judgment about what you say to anyone who is ill, depending on their particular condition. But with an Alzheimer's patient, certainly if they are angry or if they are upset or if they are anxious and there is a way for you to relieve them of those feelings, you are foolish not to use it. And if it involves, whether you want to call it fibbing, or telling an un-truth, or lying, then you are a fool not to do it. I have probably did it more than I told the truth at certain times and I am actually proud of it. It worked most of the time. There is never a reason for you to have a disagreement with a dementia patient. That should be a rule that everybody follows. You can't win the argument, so don't have it. It's that simple.</p>
PI	<p>I want to quote you on that (laughing).</p> <p>At what stage of the illness did you begin or would you begin fibbing to the patient to avoid agitation? Why? What would trigger you to incorporate this into your caregiving? Did you find it difficult to use this technique and why? I am happy to come back to the last one.</p>
Mr. Brown	<p>I started doing it as soon as I understood what I was dealing with. Immediately. So, basically, I always did it (laughing). And I realized that I needed – well, let's</p>

	see, how do I explain this. My mother probably had Alzheimer's disease for three-ish years or so before I realized that she had it. My father's illness and subsequent death was the trauma that really kicked it into what I call "obvious gear" because that's when I understood clearly that she had dementia, and I was pretty sure it was Alzheimer's. So it was at that point, since I knew, I started managing her. And managing her meant lying when it was appropriate to lie. When was it appropriate? When she was angry, when she was upset, when she was agitated, when she was going to do something that may have proved harmful to her. When she was imagining situations that didn't exist, when she was accusing other people of doing things that were harmful to her, or anything even remotely related to those things.
PI	Thank you. Did you find it personally difficult to use this technique?
Mr. Brown	Oh my goodness, no.
PI	Why do you think that's so?
Mr. Brown	I guess it's because I'm a natural born liar! (laughs)
PI	(laughs)
Mr. Brown	I don't understand why you wouldn't use it.
PI	Yeah. What is your biggest concern about withholding any potential information from the patient? Yes?
Mr. Brown	I can't imagine that I had any. And I don't know that lying, in this therapeutic manner, has to be in any way equated with withholding information that one believes the patient has to have. One can certainly have a discussion with the patient; get the necessary information across, but maybe without all the detail, maybe by dressing up some of the unattractive detail, et cetera, et cetera. So I don't see that those two things have to be connected.
PI	Mhmm. What would, if anything would make you reluctant to tell a fib or a lie? And do you think it is wrong for a caregiver to lie to an Alzheimer's patient in order to spare them the anguish of hearing the truth? And I know that you touched upon these points; I'm merely going through the-
Mr. Brown	Mhmm. I can't think of a situation in which – I mean there were times when I had to tell my mother that somebody died. And I found a way to tell her. Sometimes I didn't include a lot of detail, because you wouldn't do that with an Alzheimer's patient anyway. And sometimes I would even take her to the funeral. I would find a way to tell her kindly that somebody had passed. And the reason I did it was because I was afraid someone else might mention it. Or say something about it, and if I hadn't told her then it would present a problem. Now, she might not remember that I had told her, so I would have to then - if she confronted me, find a way to kindly remind her that I had told her. Because you never say to an Alzheimer's patient, "Don't you remember?" You don't use that word ever. So you can say, "We talked about this. We – yes, yes, I'm thinking about it now and we- we talked about this." And she would hear the kindness in my voice, and because she was my mother, and we had a good relationship, she would agree with me because what she heard was that I desired agreement. So even if she didn't remember, she would go along. So there are ways – your job as a caregiver for an Alzheimer's patient is to be a step ahead. That's your main job. You need to be ready. When they dish it out you need to be ready to catch it, and you need to be

	able to respond immediately.
PI	Absolutely. I have two more topics to cover. When the patient becomes confused and says things that are untrue, do you typically correct him or her? Do you respond as if you are accepting the patient's reality? And some other topics you may want to touch upon: when you offer corrections, how does the scenario typically play out? And how do you feel about doing so, or how do you feel about the situation? And how do you feel about letting the patient live in his or her own world?
Mr. Brown	<p>Well from back to front, no one can prevent the patient from living in their world. So considering, if you were going to dwell on that you will get nowhere and you will not be helpful. They have a reality and you have to figure out how to insert yourself in that reality, that's your responsibility. It's not theirs. When it's necessary to give them information, or because they may have misinformation, again it's your job to manage that situation.</p> <p>So for instance, when my mother received a letter that talked about her not being able to drive anymore, which is one of the biggest things in the whole world with an Alzheimer's patient! , she was of course very upset. The reason she got the letter was because of me. Well we couldn't tell her that. So she kept saying to me, "Who would write such a letter? Why would anybody do this to me?" And so the information that was delivered had to take a different route. It had to take - Obviously you know, I 'didn't know who wrote the letter. How would I know who wrote the letter?' Fortunately, the letter came from the Motor Vehicle Bureau, but I engineered that cause I knew nobody's name would be on it. But I said, "You know, this may just have to do with your age. " It was my job to figure out alternatives. And she would think a minute, and maybe drop back, and then of course she would forget that, and it would come up again, and again, and again, and again, and again, and again until finally it dissipated. It took a very long time to dissipate. But again, it's always the caregiver's job to figure out how to get around all these things.</p> <p>And what I would add to that is, obviously because I am a group leader, I am very much in favor of groups and I'm going to tell you why. When I first went to group – a long time ago now – I was very dissatisfied with it. The majority of the discussion I group, 90% of it centered around emotional wellbeing, which is this kind of clinical non-clinical term. Being a more practically oriented person, I thought, "This is bulls***. This is not helping me. I need to know what to do with this woman." And my biggest complaint was I need to know how to talk to my mother, because I didn't know. I didn't know what to say. I didn't know how to respond. I didn't know what to initiate or not initiate. I didn't know how to manage conversations. And so I sat in group for a while and I listened. I wasn't particularly emotionally distressed; I just felt – I was [looking for] practical, useful information that I needed for everyday life. And so I spoke to a friend of mine who was a therapist and he said to me, I think his exact words were, "[Mr. Brown], you idiot, you have no experience with group. Why are you telling me this? Why aren't you saying it in group? That's what you're there to do. Now go to group and tell them what you just told me." (Laughs) and I did. And within probably three months the entire discussion it the group changed and it became a much more well-balanced</p>

	discussion of practical issues of handling and managing Alzheimer's patients, and the emotional stresses that we suffered as caregivers.
PI	Wow. Wow. I'm glad that that happened.
Mr. Brown	Well if it hadn't happened I probably would've dropped out of the group.
PI	True.
Mr. Brown	But actually, the other point is, so in doing that, and this is what we do in my group. And I do have heavy focus on the practical. But in doing that, you learn from other people and what they've been doing. They handle this problem this way. They handle this situation this way. They managed this family of confusion in this way. They managed the doctor's visits in this way. They managed the nursing home visits or the resident's visits in this way, or the problems with the social worker in this way, or the problems with the attorneys in this way. And that became a very, very large part of the discussion course. The other thing was we were all talented in one way or another, so we helped each other. So when for instance, I'll call her Alice, when Alice, was having trouble [Care Facility Name redacted]- I'm sure I'm not supposed to say that, but I'm saying it deliberately in recording-
PI	Yes-
Mr. Brown	I said to her, "Oh Alice, we have to write a letter dear. And I'm going to do it for you, because it happens to be something that I'm good at." And I wrote a letter. And the day they received the letter they called her. They asked her to please come at her convenience to speak to them and the problems that she was having with her mother's care were completely cleaned up in 24 hours. Now all that happened was, she got the benefit of experience that I already had, but then she was able to help someone else in the same way. And then our group literally became this kind of helper group, and the group did what a group is supposed to do: it started to run itself. That's what a group is supposed to be able to do, in my opinion. In my uneducated, nonclinical opinion. When the group members can all provide support and information to the other members without the facilitator, the group is successful.
PI	No, I really - I appreciate you sharing. I just have one more topic to go over-
Mr. Brown	Sure-
PI	And some of it speaks to what you just said, along those lines. The first question is what is your opinion on the use of therapeutic lying by medical professionals?
Mr. Brown	My opinion on the use or therapeutic lying and..?
PI	Lying by medical professionals.
Mr. Brown	Oh, medical professionals.
PI	Yes, I'm sorry. Should this be reserved for medical professionals, non-medical caregivers or both? And why? I'll let you touch upon those points first before going through the rest.
Mr. Brown	I think that medical professionals have to use it judiciously when providing direct care to the Alzheimer's patient. However, they should not use it in speaking to the caregivers, unless they detect that the caregivers themselves are unable to handle the information. So maybe in those cases we're not exactly talking about lying, we're talking about managing the information. They have to tell them the truth. But managing the information in a smart way so that the caregivers will be able to

	<p>do their job. We don't want to render the caregivers useless and scare the hell out of them, so that they're so crazed that they get anxious and can't do what they're supposed to do.</p> <p>So I think that again, all of this has to be done smartly. In my experience with physicians what have I seen? I've seen some absolutely superb geriatricians do a wonderful job with this, and then I've seen physicians who I know are good physicians, from a medical standpoint, they just don't have the personality for this. They just get – they can't do it. They do not do a good job with this. So, to be fair to the physicians, this is going to be true across the board with people period. I don't think we can divide the medical community and the non-medical community and say, you know, well these people will do it better than these people. I don't think it works that way. But that's certainly been my experience.</p>
PI	Would you or do you encourage any medical aides to incorporate therapeutic lying into their caregiving?
Mr. Brown	Oh, absolutely.
PI	And is there a major difference between a familial caregiver or a medical professional using this technique?
Mr. Brown	<p>There are differences, yeah. The medical professional has to be, I believe, much more judicious about how they do this. I think they have to do it in certain cases, because again, the reason you do it is because you want your patient – you don't want your patient to be anxious and totally crazed about information that you're giving them. But the other reason that you do it is because you want to maintain your relationship with the patient so that they hear you and they can work with you. If they get anxious they're not going to hear anything that you said. And your visit is done. You're going to tell the caregiver, whoever is with the patient, whatever information they have to have and then you're going to send them on their way. So you want to make sure – I can tell you the technique that I developed with my mother's geriatrician. And it took time for me to figure this out. I would – with every visit I would send a memo to him, to his office to go in my mother's folder, describing circumstances since my previous visit, offering suggestions or information about what I thought we needed or asking questions, et cetera. Or even asking about certain drugs or treatments. So the agreement that I had with the physician was that while he was with my mother examining, I was with her the entire time. There was a never a time that he was with her alone; I was always with her. But I would not interrupt any conversation that he had with her. I would not insert myself into any conversation or situation; I would just sit there and take notes. Because he would ask her questions, she would answer, or a lot of times the answers were not accurate, but in many cases he could not have known that. When I got home that evening I would transcribe my notes and I would send those notes to the physician so that he would know exactly what was accurate and what wasn't accurate in that visit. And it took me a while to kind of figure out that this needed to happen, but once we got the rhythm going, it was excellent. It was excellent. It worked really, really well. And what I said to my mother was, each time, "Now, you know, when we go to the doctor, I never remember what he says. Do you remember what he says?" And ordinarily, you would never say to an Alzheimer's patient do you remember something, but this was an instance in which I could say,</p>

	<p>“Do you remember all the stuff he tells you, cause I don’t remember it.” And she could say no she didn’t remember it. I said, “So I’m going to take notes, okay? You sit – you have to talk to him. But I’m going to take some notes so that we can go over what he tells us to do when the visit is over.” And she would say, “Okay, that’s a good idea.” And of course I would have to repeat what we were going to do each time, and it worked. In fact, it worked very very well. And so in group, I said “this is what I’m doing.” And then everybody started to do it. But I also had a cooperative geriatrician.</p>
PI	Right. That’s, I mean it’s brilliant.
Mr. Brown	No it wasn’t brilliant!
PI	It’s very-
Mr. Brown	It’s born out of necessity.
PI	Of course. Of course. It’s very intuitive though. And just one last thing. Do you feel better about lying or fibbing when it’s described with a medical term such as therapeutic lying or therapeutic fibbing? And having this, you know, having this institution of ‘this is a set technique’ rather than-
Mr. Brown	Oh no. I think you should call it what it is. It’s therapeutic lying. Period.
PI	What I’m asking is: would you feel better about using this technique if it is an established technique with medical terminology as opposed to something that people do intuitively?
Mr. Brown	Oh, would I feel better about it? I don’t – I guess my answer is I don’t need it to be an established codified technique to feel better about it.
PI	Just out of curiosity, if you feel comfortable sharing, how do you feel about that question, I supposed in general.
Mr. Brown	Oh, I’m fine with it. There are certainly those who would not necessarily feel comfortable going outside of what’s called “medical advice”. I’m not one of those people (laughs).
PI	Those are all my questions for today. Is there anything else - Do you have any questions for me, or is there anything else you’d like to add before I close the recording?
Mr. Brown	<p>I can’t think of any questions I have certainly on this topic. I think I’ve been clear – lie, lie, lie, when it’s going to make the patient feel better or it’s going to be good for the patient. So, that sums up what I think. I think that the job of a caregiver is a next to impossible job that you can never get perfect. And I know that I was by myself as an only child with a father who had just died, and I can tell you now, even though my mother’s been dead for three and a half years, I can still recount all the situations in which I think I’ve made a mistake, and where I think I made a decision I wish I hadn’t made. I don’t think it ever exactly goes away. Did I do a good job? People say I did. Do I think I could have done a better job? Yeah, I definitely do. But that may just be me, as a particular personality. Did I get my reward? Yes, I did, and I’ll tell you in a short version how I got it. There came a time, as with many Alzheimer’s patients, where my mother didn’t know my name anymore. And it took me months to realize it, it just hit me one day and I said “she doesn’t know my name! (Laughs) she doesn’t know my name. And she knew who I was, she just didn’t know my name, and of course that’s a common symptom. And when I would – she was in [facility name redacted] in those days – and when</p>

	I would come to visit, as soon as I would appear at the door, she would with arms outstretched she would say, “He’s my son! He’s my son!” That’s about the greatest reward I think you can have if you take care of someone. She was happy to see me; I made her feel better. And that’s what the whole exercise is about.
PI	Thank you very very much for sharing and participating. I’m going to shut off the recording right now.
Mr. Brown	Okay.

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