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Telling ‘a good’ or ‘white lie’: the views of people living with dementia and their carers

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Telling a ‘good or white lie’: the views of people living with dementia and their carers

Abstract

Objective: A common symptom of cognitive decline in people living with dementia, or people with memory problems, the cause of which has not yet been diagnosed, is the person repeatedly asking for loved ones who are deceased or making statements that are incorrect. Carers are then faced with a dilemma, do they avoid and distract or ‘correct’ the person and tell the ‘truth’, or tell a lie. This paper explores the concept of lying from the perspective of people living with dementia in the community and their informal/unpaid carers.

Methods: A descriptive qualitative study utilising focus groups (FG) to collect the data was conducted. Three FG’s with a purposive sample of people with memory problems (n = 14) and three FG’s with informal/unpaid carers (n = 18) were undertaken. Qualitative content analysis was used to analyse the data.

Results: All participants considered that blatant lying with the intention to deceive and do harm is not acceptable. However, telling a ‘good lie’ or ‘white lie’ to alleviate distress was in certain circumstances considered acceptable. The intention behind the ‘lie’ in their view had to be to do good, and the informal/unpaid carer telling the lie had to really ‘know the person’ and be cognisant of family preferences. Some informal/unpaid carers acknowledged that it may be acceptable for health care professionals to tell a ‘good lie’ or ‘small lie’ in certain circumstances. However, health professionals need to ‘know the person’ and need to consider informal/family caregivers’ wishes.

Conclusion: Lying was only considered acceptable in the context of knowing the person and when done with the intention not to harm or deceive, undertaken with empathy, and only for the purpose of mitigating the person living with dementia’s distress.

Key words

People living with dementia, Therapeutic Lying, Informal/unpaid carers, Informal carers of people living with dementia, Qualitative research

Introduction

It is estimated that 50 million people worldwide have dementia and this figure is expected to increase to 152 million by 2050 (World Health Organization, 2017). This prediction is conservative as many people, particularly those in the early stages of dementia do not have a formal diagnosis (Prince et al., 2013). In this study the term ‘people with memory problems’ is used rather than ‘dementia’ as participants who did not yet have a formal diagnosis of dementia were included. The perception of reality of a person living with dementia may as the condition progresses, become confused with memories from an earlier period in their life, and these memories become the person’s present-day reality. Mackenzie et al. (2015) refers to this as ‘time-shifting’ and often these ‘time-shifts’ are associated with high emotional events, which are more easily recalled. For example, the person forgets that their spouse has died, for them that person is still alive, and they therefore may be looking for and asking for this person. This can generate high anxiety levels for both the person living with dementia and their informal/unpaid carers. Consequently, carers are faced with a dilemma: do they avoid and distract, ‘correct’ the person, tell them the ‘truth’ or tell them a lie.

Literature Review

Lying as a deliberate form of deception is described as having generally three key elements; it communicates information, the person communicating the information intends to deceive, and the person receiving the information perceives the information to be true (Ludwig, 1965, Stokke 2013). Lying per se therefore is not considered beneficial, but morally problematic. Lies are usually explicit untrue statements that are uttered with the aim to deceive, but

deception is also possible without explicitly telling untruths. It is possible to mislead persons by setting them up to draw incorrect conclusions from ambiguous or incomplete statements or actions. Lying therefore encompasses both explicit lies and implicit misleading (Mahon 2015, Stokke 2013). In contrast to lying to deceive, a ‘white lie’ is defined as ‘a lie that is told in order to be polite or to stop someone from being upset by the truth (Cambridge Online English Dictionary, 2015). In the context of dementia this is similar to what is sometimes referred to in the literature as ‘therapeutic lying’, where the goal is to alleviate the distress of the person with dementia (Stubbs 2013). Such lies are typically underpinned by empathy for the person with dementia in that lying is seen as a deliberate intervention with the goal of increasing the person’s well-being (Day, James, Meyer, & Lee, 2011; Green, 2015).

There are however significant ethical concerns associated with the practice of ‘therapeutic lying’ (Culley, Barber, Hope, & James, 2013), because lying is generally considered an ethically problematic act. However, different ethical frameworks, such as deontological (Kant 1785/1996), virtue ethical (Aristotle 2000), utilitarian (Mill 1863/2003) and care ethical (Gilligan 1982) positions, would assess lying differently. Deontology prohibits lying because it is intrinsically wrong; virtue ethics because it is not what a person with virtuous character would do. Utilitarianism is concerned about lying because it tends to have negative consequences, and care ethics because lying may impact caring relationships negatively. Deontological positions are most absolutist in their prohibition of lying; Kant (1785/1996) famously argued that lying is not ethically permissible under any circumstances. The anti-paternalistic principle-based approach endorses a similar deontological position (Beauchamp & Childress 2012) although it might allow for some exceptions. Despite general reservations, lying might be permitted by utilitarianism under certain circumstances, if it can be shown that lying has positive consequences in the situation in question, such as better health and wellbeing outcomes. Virtue ethics might allow lying if it can be shown that persons of integrity and good

character, such as loving informal carers or committed professionals, would consider lying appropriate in specific circumstances. Care ethics might consider lying acceptable if it sustains and strengthens a caring relationship in a particular case, as judged especially by the realisation of reciprocal and genuinely caring attitudes. Echoes of these positions can be found in the literature on ‘therapeutic lying’. A deontological stance seems to be associated with positions that argue that ‘therapeutic lying’ is a ‘euphemistic misnomer’, as lying is not a therapeutic endeavour (Sperber, 2014) and that lying threatens a person’s autonomy (Brannelly & Whitewood, 2014). Utilitarian and virtue ethical positions are implicit in contributions that argue that ‘therapeutic lying’ may be acceptable when lying aims to reduce negative consequences for the patient or when an attitude of compassion underlies its use (Stubbs, 2013; Tuckett, 2012; Turner, Eccles, Keady, Simpson, & Elvish, 2017; Williamson & Kirtley, 2016).

The utilitarian question of the overall balance of consequences of therapeutic lying is prominent in the literature, as are care ethical considerations regarding the relationship impact of lying. Some researchers suggest that therapeutic lying may compromise the trusting relationship (Barnes & Brannelly, 2008; Feil & Altman, 2004; Schermer, 2007). Green (2015) found that informal carers stressed that the context of the lie matters, flagging the importance of really understanding and knowing the person before deciding to lie. Green (2015) also found that irrespective of the impact this approach might have for informal carers, the benefits of reducing emotional upsets or agitated situations for the person living with dementia outweighed any other ethical concerns. The literature also reveals that people living with dementia perceived that lying was acceptable if it was in the person’s best interest, but not if it caused distress or devalued the person (Day, James, Meyer, & Lee, 2011). Yet others highlight that a therapeutic impact for the person living with dementia may be assumed but may not always be actually confirmed (Sperber, 2014). There is also a concern that those who consider lying to people with dementia as acceptable, are subject to the discriminatory influences of ‘dementia-

ism' and the consequent 'othering' that arises when people distance themselves from the reality of the lived experience of others (Brooker 2003; Higgs & Gilleard 2014).

The degree of cognitive impairment experienced by the person living with dementia is identified as an important consideration in determining whether lying is an appropriate strategy. Even within some deontological frameworks there is an acknowledgement that increasing cognitive impairment limits capacity and autonomy and can justify lying (Carson, 2010). Alternatively, a utilitarian framework can also underpin this distinction; for example, as dementia progresses and capacity diminishes, if a person is not aware of being lied to, and has lost their ability to process difficult truths in a constructive manner, the potential benefit of the lie becomes foregrounded over its potentially detrimental aspects (Kartalova-O'Doherty, Morgan, Willetts, & Williamson, 2014). For some writers however, any type of lying is considered as deceptive and problematic, regardless of the person's cognitive understanding (Bush, 2003; Kitwood, 1997).

In the context of formal dementia care settings, James, Wood-Mitchell, Waterworth, Mackenzie and Cunningham (2006) concluded that lying was a widespread approach adopted by health care professionals. These authors justify the use of therapeutic lying once the aim is to improve the life of the recipient and developed a set of 12 ethical guidelines governing its use in formal care. Health care professionals however often face challenges in interpreting ethical guidelines when communicating with patients with dementia (Day, James, Meyer, & Lee, 2011; Elvish, James, & Milne, 2010; Tuckett, 2012; Turner et al., 2017). O'Connor, James and Caiazza (2017) recognising the complexities and challenges surrounding the use of therapeutic lying in the real world of practice, created a hierarchical needs-based decision framework for health care professionals. In this framework, therapeutic lying is identified as an acceptable option, albeit a final one, deemed to be appropriate when done in the person's best interest. The utility of the framework in practice has nevertheless yet to be fully

determined. More recently, James and Caiazza (2018) describe a training programme developed to help clinicians understand the implications of lying. As a result of the training the clinicians became aware that they lied more often than they realised, had more of an appreciation as to the ethical dilemmas surrounding lying and seemed to have a better understanding of the need to frame the use of lying within a patient centred approach.

Kartalova-O'Doherty et al. (2014) identify a number of factors to consider when deciding to lie to a person with dementia. These include who is delivering the information; when is it delivered, in terms of dementia stage and timing; how and/or the manner of the communication process; why or purpose of the lie; and where the lie takes place e.g. home or residential care. Ultimately the literature indicates that the appropriateness of therapeutic lying can only be determined on an individual basis (James et al., 2006; Sprinks, 2013; Williamson & Kirtley, 2016). This is further endorsed in the UK Mental Health Foundation report (2016) which supports the use of 'untruths' in dementia care if they are used in the best interests of the person living with dementia.

In summary, the decision to use and the acceptability of lying is a complex issue. Few studies have explored the use of this approach from both the perspective of people living with dementia and informal/unpaid carers. Furthermore, as identified by the UK Mental Health Study (2016), little research has explored this topic in the context of people with dementia living in the community. This paper presents the qualitative findings of a larger mixed methods study which explored this issue.

Aim

This study explored the experiences and perceptions of people with memory problems and informal/unpaid carers, living in the community on the use of lying.

Methodology

A purposive sample of people with memory problems living in the community was drawn from dementia advocacy groups in the Republic of Ireland and from Dementia Northern Ireland (NI). Likewise, a purposive sample of informal/unpaid caregivers were also identified. In the Republic of Ireland this was again drawn from dementia advocacy groups and the Health Service Executive, and from the Dementia Services Development Centre in Northern Ireland.

An interview guide developed from the literature was used to guide the focus group (FG) interviews. The CORTE interviewing framework (Murphy, Jordan, Hunter, Cooney, & Casey, 2014) was used to guide the interview process with people with memory problems. This guide consists of four main areas; gaining COnsent, maximising Responses, Telling the story, and Ending on a high (CORTE guide). This process maximises the meaningful involvement of people living with dementia/memory problems, ensuring that their voices are heard. Two members of the research team attended each FG. One acted as moderator and conducted the interviews. The other (assistant moderator) listened to FG participant perspectives, gathered demographic details and took notes on group dynamics. Each FG took approximately 60 minutes including opportunities for participants to take breaks.

All interviews were transcribed verbatim. Analysis began by reading each transcript which were then open coded. Each code was then examined and overlapping codes were collapsed, to form larger inclusive categories. This process enabled a hierarchical structure to emerge showing categories and their subcategories. The final categories were then organised into '*meaningful clusters*' (Hsieh & Shannon, 2005, p.1279) that '*best fits the data*' (Sandelowski, 2000, p.339). The computer software package NVivo 10 was used to assist the storage and management of the data. To further enhance the credibility of the study, participants were invited to comment on a lay summary of the final report. The received comments endorsed the study findings. Ethical approval was obtained from the National

University of Ireland, Galway and the Office for Research Ethics Committees Northern Ireland. Informed consent was obtained from each participant and process consent was utilised.

Findings

Three FG's with people with memory problems (n = 14) were undertaken. Just over half (63%) were female (n = 9) and 69% (n = 9) were in the 70-80+ age bracket. The demographic details of the sample are presented in Table 1. Three FG's with carers of people with memory problems (n = 18) were also undertaken. Most participants were female (n = 13, 72%) and in the over 50 age bracket and most (69%, n = 11) had been carers for less than 4 years. The demographic details of the sample are presented in Table 2. To ensure that the views of people with memory problems were given due cognisance, the findings are divided into two parts; first, perspectives of people with memory problems and second, perspectives of informal/unpaid carers.

People with Memory problems (PWMP)

Data analysis revealed two categories: the '*acceptability of lying continuum*' and '*respectful lying*'.

The Acceptability of Lying Continuum

This category describes the extent to which participants felt that lying was acceptable or not.

Participants talked about 'not telling the whole truth' and used language such as a 'good lie' or a 'small lie'. Participants' views regarding the acceptability of lying ranged on a continuum from 'not acceptable' when the intention was to deceive and do harm to 'acceptable in some' circumstances.

The opinion of those who believed lying was not acceptable was grounded in their personal beliefs and values about the truth and being truthful. These participants wanted to be told the truth irrespective of the situation.

I certainly wouldn't think it's acceptable to tell anyone lies, I don't care what the situation is, it's not acceptable. (FG3 PWMP)

Nevertheless, during the course of their interviews some of these participants tempered their views on lying indicating that minimising truth-related distress was the sole rationale for when lying could be acceptable.

No matter what you do he's gone away or she's gone (died), right, so if it's going to help her or help me, do you know because what good is making her suffer because she'll forget all about it again... (FG1 PWMP)

Those who considered lying as acceptable made clear that it was only to be used to prevent the person becoming distressed. For them the context and outcome mattered more than always telling the truth. A distinguishing characteristic of acceptable lying was the underlying intention behind the lie.

I don't believe in lying.

Int: Yeah, very good OK.

Leave the person happy.

Int: If it's to make the person happy?

Make her or him happy.

Int: Happy, then it is acceptable?

It's worth anything.

Int: It's worth anything?

I think. (FG1 PWMP)

Approaches considered acceptable when not telling the whole truth were: distracting, moving the conversation on or avoidance.

I think maybe even a wee bit, even move it around a bit you know...maybe change the subject a bit...Try to, yeah try to distract. (FG3 PWMP)

...They get upset and they're unhappy, you're better off with a smile and only small lies.

Int: A small lie...

A small lie.

Int: And that's, I think that's the important part (Name), it's the type of lie?

You've got to gauge it. (FG1 PWMP)

The stage of dementia, or more importantly the person's awareness of their condition, was perceived to be another critical factor in determining the choice of strategy. Participants equated the stage of dementia with awareness, in that if the person was likely to become aware that they were being lied to, it was never acceptable.

...we're all different here. And personally at the stage that I'm at if I hear about the death of somebody or something like that there I would appreciate being told ... because I'm at that stage. (FG3 PWMP)

However, for some participants, if the person had diminished awareness and was likely to be distressed when told the truth, then it was deemed more acceptable to use a 'white' lie.

Respectful Lying

Participants reported that respecting the person living with dementia's individuality and dignity should be a fundamental guiding principle.

We have to remember about the person's dignity, you know and you can't take that away from them by deliberately telling them lies... (FG3 PWMP)

The action taken must also be informed through knowing the person and what matters to him/her. In addition, if the person is no longer able to determine what is right for him/herself, the action to take should be decided in consultation with the person's family or significant others.

...it's a difficult situation no matter what way you go...it comes down to the individual ... so it's knowing him or knowing her, the relationship with the carers and the family and doing your homework before you go there, you know. (FG3 PWMP)

However, some participants commented on the negative impact lying might have on their relationship with and trust in carers, indicating the significance of care ethical considerations. In addition, they were concerned that the whole notion of being lied to made them feel more vulnerable and at risk of further losing control and autonomy.

Informal/Unpaid Carers

The analysis of the data from carers also revealed the category '*acceptability of lying continuum*', as well as two other categories: '*approaches to managing distress*' and '*empathetic deception*'.

Acceptability of Lying Continuum

Similar to people living with dementia, for some carers' their beliefs about 'truth' and 'being truthful' was an influencing factor on their views that lying was not acceptable. They expressed the care ethical concern that lying could cause mistrust, impacting negatively on relationships. They also worried that seeming to accept the person living with dementia's mistake could worsen their confusion. The ambiguity of dementia, the constant changes in the person's capacity, added to carers concerns about inadvertently making it worse.

I do have qualms...I have difficulty with it, especially if it's taking him further into where I feel is confusion. I feel...that maybe there has to be some flag post sticking

up somewhere out of the fog, you know. So I'm unhappy to lead someone further into the fog all the time. (FG2 Carers)

For some other carers however, telling a 'good lie' was deemed acceptable as long as the intention was to minimise truth-related distress. This acceptance came with the caveat that knowledge of the person was a fundamental prerequisite before lying could be used as a strategy.

...I'm not caring for a stranger, I know what she thinks ... So if she goes well "where is (Daughter's name)" and I can know what she will accept about where (she) is? ... She will only accept that my brother is working, he is not allowed to be enjoying himself.

Int: So you tell a white lie.

Yes I do. (FG1 Carers)

Carers were speaking in context of experience where they were faced with the dilemma of what to do, what worked best and had the least negative impact on the person living with dementia.

I have no qualms about telling a massive whopper. If it keeps the mood sweet ..., I think if their mood is sweet, it is important. (FG2 Carers)

For some, distracting or not telling the whole truth helped prevent a situation escalating to crisis point into behaviours that challenge.

My husband is very gentle ...I had this awful incident last year and I had to get the doctor for him ... by the time the doctor came he was ... grand and he said "I would never hit a woman" ... but when he's going through this awful thing and the face changes completely and he's a completely different person ... that's the frightening

part of it you know... And it's very important as well, when they're agitated to be able to press the right buttons... (FG1 Carers)

Some participants described a strategy of not actually lying but going with the flow or going with the person to minimise distress. In this context they did not challenge the mistake but deliberately went along with it.

...mother was asking for Dad Now he's dead three years. So I kind of thought well the last time I told her that he was dead we had to go through the whole grieving process ... So I thought well OK this time now I'll just kind of go with the flow...I just didn't want to put her through the whole grieving process again. ... (FG3 Carers)

In relation to the acceptability of formal carers telling lies to people living with dementia, carers felt that in certain circumstances it was necessary for them to lie. They felt that they, as the next of kin/or family member, had a responsibility to convey their knowledge of knowing the person and tell them what the person would want and they expected that the formal carer would respect their wishes.

...if a carer comes in the door? I'll tell her where mother is at and I'll tell her what's her reality at the minute ... and try and go along with that if you can... And I'll expect that they'll respect that, I would be very disappointed if somebody came along cold or whatever and said something that would bring mother too much to her reality ... (FG3 Carers)

Approaches used to minimise distress

Participants described how they used reframing, moving the conversation on or distracting strategies to minimise truth-related distress. The strategies employed varied and were learnt through trial and error. They emphasised that there was no one correct approach but rather

actions were shaped by: their knowledge of the person, his/her reaction, the specific context, and the stage of dementia.

I remember when Dad would be asking, I would distract him, he'd say "where is mum", I'd kind of switch it around quick and I'd say something completely (different), you know. (FG1 Carers)

... now a sister of mine died ... he was asking about her one day, he said "oh where is she now" ...I changed the subject then to something else ... and then he forgot all about it ... (FG3 Carers)

Some carers had attended training sessions to help with their understanding of and ability to care for people living with dementia and had picked up some suggestions with regards to how to respond. For others, learning to let the 'mistakes' that the person living with dementia made 'go' was seen as part of a learning process and also part of accepting that their loved one had dementia. Reaching acceptance was a painful and distressing journey for carers and learning not to react to mistaken statements meant having to suppress their natural response.

I know at the beginning we were a bit corrective of mother but I have been to some of the seminars and things like that and I was talking to my wife who hadn't been to those and she was more corrective and I was trying to pull her back. Letting it go really. (FG2 Carers)

...I have to say in the first couple of months I was like a briar, I could not accept that she'd forget this, that or the other ..., you'd tell her something in the morning and that evening you might remind her again about it...and it took me a while, I have to be honest about it, it took me a while to more or less have the patience to more or less deal with it. (FG3 Carers)

Empathetic Deception

The strategy of not challenging the person and telling them a lie, (except if it put the person at risk), was used with empathy and not to deliberately deceive. It was evident that a balancing act was required to meet the person's care needs between - 'keep them safe', and 'keep them happy'. Participants viewed 'lying' as kinder because it reduced and allayed the anxiety of the person living with dementia and reassured them that everything was alright. The person's awareness of their dementia also shaped the carer's approach and as a consequence this changed as the person's memory deteriorated.

...she was still in the awareness of, at a stage where she could not totally remember "she's dead", but had a sense of she was so it wouldn't have helped at that stage to be giving her a story. But further down the line then...if we'd mention them we'd mention them as if the person was still alive.... (FG3 Carers)

My mother...She does ask, you know 'what about so and so'. And at the start I was reluctant to break it to her "oh they're dead" but there's no difficulty now, she just accepts, there might be a moment "oh dear, I must have forgotten that". (FG2 Carers)

The personhood and individuality of the person was stressed. To their mind what mattered to the person living with dementia must be reflected in the approach taken. It is not surprising therefore that some questioned the value of having a set of hard and fast rules.

I don't understand how there could be hard and fast guidelines because it's going to be different depending on what type of dementia you have ... and the relationship with the person. (FG2)

... I don't think there's any wrong way or right way to deal with it, everyone has to deal with it the best they can. (FGI Carers)

Discussion and Conclusions

In this study informal/unpaid carers and people with memory problems considered lying along a continuum, from not acceptable when the intention is to deceive and harm, to acceptable at times when the intention is to benefit and minimise harm. Despite the expression of concerns about the use of lying from some participants, most agreed that the latter (lying to minimise harm) and only the latter, could be acceptable in the context of people with memory problems. This finding concurs with that of other studies (Culley et al., 2013; Day et al., 2011; Green, 2015; James et al., 2006; Taylor, 2007; Tuckett, 2012; Turner et al., 2017). In our study participants focused firmly on the intention behind the lie and its impact on the persons with dementia which for them was crucial. Telling a lie was only considered acceptable when done with the intention not to harm or deceive, undertaken with empathy, and only for the purpose of mitigating the distress of the person with dementia.

The moral costs associated with normalising lying were acknowledged by participants. Choosing not to correct a person and tell them the truth, or tell a lie was not a decision that either carers or people with memory problems selected or accepted lightly. A general preference for the least intrusive form of engaging with lies was evident, and this seemed to be linked to an acknowledgement of the crucial moral importance of truthfulness and respect for dignity. The menu of strategies used by carers included reframing, 'going with the flow'/going with the person', moving the conversation on, or distracting and telling a 'good lie'. It was clear that some carers struggled to find viable solutions when faced with the dilemma of how to maintain the dignity of the person living with dementia and minimise their distress. For most,

the strategies used had evolved over time on a trial and error basis as they struggled to come to grips with the changing impact of dementia. However, it is important to recognise that strategies such as expecting the person to '...forget about ' their relatives demise may not always be effective as this can become a fixation for the person with dementia if adequate possibilities to express grief is not afforded. Furthermore, lying, even if it is mostly well meaning, may be consciously or unconsciously driven by the carers own needs to self-manage their stress rather than the needs of the person with dementia.

In the context of health care professionals, some writers highlight the need to better prepare and train health care professionals to communicate more effectively with people living with dementia (Tullo, Lee, Robinson, & Allan, 2015) and the importance of using collaborative interprofessional decision making (Turner et al., 2017). However, training for informal/unpaid carers as to how best respond when the person with dementia makes statements which are incorrect appears to be somewhat lacking, none of the informal/unpaid carers in our study reported receiving such training. There is an urgent need therefore to provide support and training to informal/unpaid carers living in the community, on what they might expect as the disease progresses in terms of time-shifting and fluctuating realities for the person living with dementia and equipping them with a repertoire of skills to address same. These skills should include the management of stress related caring and the ability to identify when their personal needs and the needs of the person with dementia might conflict and how to honestly and acceptingly engage and deal with such conflicts. Such exploration should also include an honest and open personal exploration whether, and if so when, distracting, misleading or telling a lie might be acceptable for them and the person with dementia, in light of general moral concerns as well as their personal situation and value commitments. This may help informal carers come to a well-reasoned stance on the use of 'white lies' rather than unwittingly slipping into a

practice of using them.

A few participants with memory problems and carers expressed concerns that telling a 'white lie' or 'a good lie' might cause mistrust, impacting negatively on relationships, a position that reflects crucial care ethical concerns. As Noddings (1984) claims, the intimate caring relationship requires the carer to truly see the person they are caring for, get attuned to their particular needs and support them in their development. Telling what our participants referred to as 'a good', 'small' or 'white lie' could be considered an action that alienates carers from the genuineness of that relationship and stands in the way of the open reciprocity between carer and the person with dementia. Nevertheless, the benefits of minimising distress for the person with memory problems offset these concerns for most participants. Participants suggested that respecting the individuality and dignity of the person living with dementia was compatible with telling a 'good lie'. They felt the deep knowledge they had about the person, their past and their current experience allowed them to use lying in a genuinely caring and respectful manner. Such attunement to individual need was given as an explanation as to why neither carers nor people with memory problems favoured lying in the earlier stages of the disease, fearing this could undermine the autonomy of the person living with dementia and further exacerbate the person's confusion. The unacceptability of lying in the early stage of dementia is also reflected in the literature (Kartalova-O'Doherty et al., 2014; Taylor, 2007). For people with memory problems in our study, when awareness of their condition is still present, they preferred to be told the truth. However, the fact that carers and persons with dementia expressed acceptance of lying vis-à-vis persons in the later stages of dementia, when they would not accept it for themselves, could also be interpreted more critically, as an expression of 'othering', the subconscious distancing of healthy or less affected persons from persons with late stage dementia. The significance of the phenomenon of 'othering' has been

explored extensively in feminism (e.g. de Beauvoir 1949), post-colonialism (e.g. Spivak 1989) and disability studies, and has been linked to the subconsciously motivated dehumanisation of potentially threatening others. It has been argued that very old age, and especially later stage dementia, is perceived as such a frightening prospect that ‘othering’ of those affected occurs (Doyle & Rubinstein 2013, Higgs & Gilleard 2014, McParland, Kelly & Innes 2017, Mitchell Dupuis & Kontos, P. 2013, Pritchard-Jones 2016). In the context of this discrimination the term ‘dementia-ism’ has been coined (Brooker 2003) and the problematic role of the common ‘tragedy’ discourse surrounding dementia has been highlighted (McParland, Kelly & Innes 2017, Reed, Carson & Gibb 2017).

In relation to the acceptability of health care professionals telling a lie, informal/unpaid carers also accepted that this may be acceptable in certain circumstances. However, similar to the case of informal care provided by loved ones, they firmly believed that these health professionals should act in a way that is appropriate to the person, on the basis of good knowledge of the individual, taking into account the views of the family or informal/unpaid carers and ensuring that the intention behind the lie is to do good. Seaman and Stone (2017) highlight the complexities of deception in the context of dementia, noting that caring for people living with dementia involves dynamic interactions among a network of care providers, across various different settings. Collaborative, shared decision-making regarding the best interest of the person living with dementia is therefore critical (Tullo et al., 2015; Turner et al., 2017). In this way all key stakeholders are involved and are aware of the decision made regarding lying promoting consistency in approach (James & Caiazza, 2018). However, this is not without its challenges in particular if informal and formal carers differ substantially in their attitude towards the use of lying as part of care. In such instances it is essential that the issue is addressed explicitly and honestly, with all parties listening respectfully to each other’s

viewpoints, appreciating their knowledge and experience, while keeping the needs of the person with dementia as their foremost concern.

For people with memory problems, an individualised person-centred approach that takes cognisance of life history and preferences was considered a pre-requisite when deciding to tell a 'white lie'. This finding is reflected in the literature (James, Wood-Mitchell, Waterworth, Mackenzie, & Cunningham, 2006; Day, James, Meyer, & Lee 2011; Sprinks, 2013; Williamson & Kirtley, 2016; O'Connor, James, & Caiazza, 2017; James & Caiazza, 2018).

Notwithstanding the views of some of the informal/unpaid carers in our study, the use of lying in any form is considered unacceptable, unethical and dishonest in professional guidance literature (Pool, 2007; Sherratt, 2007; Walker, 2007). Indeed, most health care professional Codes of Conduct and best practice guidelines stress the need for truth telling and stipulate that lying in any form is inappropriate; failure to comply may bring fitness to practice into question. However, the evidence suggests, irrespective of Codes of Conduct, lying is a solution considered acceptable by many and is used routinely in dementia care (James et al., 2006; Tuckett, 2004; Turner et al., 2017), in particular in cases where distress or disorientation are the likely alternatives, and non-maleficence and compassion are the intentions (Elvish et al., 2010; Kartalova-O'Doherty et al., 2014; Sperber, 2014; Stubbs, 2013; Tuckett, 2012; Turner et al., 2016). Echoing the sentiments expressed by James and Caiazza (2018), there is an urgent need to review clinical and professional guidelines and at least recognise the possibility that in certain circumstances telling a lie may be beneficial. Such changes could pave the way to a wider and more open discourse around the use of lying and instil frameworks to assist health care professionals in deciding when telling a lie may be an appropriate approach to use to minimise distress of the person living with dementia.

In the latter stages of the disease, when memory has declined significantly, people with memory problems stressed the need for family consultation when deciding what actions to take because they knew them best, knew their life history, and knew what mattered to them most. They recommended that where possible, this consultation should be completed with the person living with dementia when they still had awareness of their condition. Carers acknowledged they should be given a voice when judging the risk/benefit of telling a 'small' or 'white lie' which had to be assessed in the context of individual needs. They were wary therefore, given the unique needs of each person living with dementia, of having specific fixed professional rules and guidelines into which they had no input.

In conclusion, the process of communication is multi-layered, encompassing emotion and meaning, as well as verifiable facts. In the context of people living with dementia, communication may be even more difficult as the person living with dementia become time-shifted and experiences fluctuating realities. Deciding how best to respond, tell the truth or tell a lie, is difficult. This paper focuses on the use of lying and is important as it captures the perspectives of people with memory problems as well as that of informal/unpaid carers living in the community. The findings reveal that blatant lying with an intention to deceive and harm is not acceptable to these stakeholders. Yet, in certain circumstances for some participants telling a 'white lie' or a 'good lie' is considered acceptable and the kindest solution. However, further research involving all key stakeholders, including professional regulatory bodies is needed to agree terminology and guidelines for the use of this approach. Clearly, regardless of terminology, lying is part of the hidden curriculum in dementia care and as such needs to be acknowledged and guidance regarding its implementation needs to be clarified, developed and tested.

Limitations

The findings are based on a small purposive sample. Including people with memory problems was an inclusive strategy given the lack of dementia diagnosis. However, it could be argued that the perceptions of people with memory problems differ from people with a dementia diagnosis as they do not fully grasp the reality of living with such a diagnosis and may also be tempted into ‘othering’ people who are more severely affected

Yet, in this study there were no clear differences in the findings as regards the acceptability of lying, between those who had a dementia diagnosis and those who did not. Future work should seek to include larger samples with those who have a definitive diagnosis to confirm the transferability of the findings. Additional research exploring the impact of this strategy on both the person with memory problems and caregiver is also warranted. The results of same will help confirm whether the best interests of both parties are served.

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