



Ethical considerations of doll therapy for people with dementia

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Abstract

The use of doll therapy for people with dementia has been emerging in recent years. Providing a doll to someone with dementia has been associated with a number of benefits which include a reduction in episodes of distress, an increase in general well-being, improved dietary intake and higher levels of engagement with others. It could be argued that doll therapy fulfils the concepts of beneficence (facilitates the promotion of well-being) and respect for autonomy (the person with dementia can exercise their right to engage with dolls if they wish). However, some may believe that doll therapy is inappropriate when applied to the concepts of dignity (people with dementia are encouraged to interact with dolls) and non-maleficence (potential distress this therapy could cause for family members). The absence of rigorous empirical evidence and legislative guidelines render this a therapy that must be approached cautiously owing to the varied subjective interpretations of Kitwood's 'malignant social psychology' and bioethics. This article suggests that by applying a 'rights-based approach', healthcare professionals might be better empowered to resolve any ethical tensions they may have when using doll therapy for people with dementia. In this perspective, the internationally agreed upon principles of the United Nations Convention on the Rights of Persons with Disabilities provide a legal framework that considers the person with dementia as a 'rights holder' and places them at the centre of any ethical dilemma. In addition, those with responsibility towards caring for people with dementia have their capacity built to respect, protect and fulfil dementia patient's rights and needs.

Keywords

Alzheimer's disease, bioethics, dementia, doll therapy, Kitwood, law, non-pharmacological therapies, person-centred care

Introduction

Internationally, the number of people with dementia is growing rapidly. Current estimates suggest that around 40 million people worldwide live with some form of dementia, and assuming that people continue to live longer, this number is expected to grow to around 66 million people by 2030 and possibly reach 115 million by 2050.¹ According to the World Health Organization,² this equates to potentially one new case every 4 s. In 2010, Alzheimer's Disease International¹ estimated the global cost of dementia as US\$604

billion (1% of global gross domestic product (GDP)). If adequate resources are to be maintained to reflect the growing number of new cases of dementia, economic costs will undoubtedly rise in proportion.

It is widely accepted that dementia is associated with advancing age and is an umbrella term for a clinical syndrome of impairment in multiple domains of cognitive function.^{3,4} While there are over 200 different types of dementia, three common sub-types account for approximately 90% of those affected.³⁻⁶ These are Alzheimer's disease (40%), vascular dementia (25%) and dementia with Lewy bodies (25%).³ As a result, clinical manifestations of dementia may vary considerably from person to person but are typically characterised by progressive loss of memory, language deterioration, poor judgement, difficulty in performing automated tasks, communication difficulties, problems with spatial awareness and changes in personality.^{4,6,7}

At present, best nursing practice for people with dementia advocates a culture of care that is person-centred.⁸ The central tenets of person-centred care are about valuing and respecting people regardless of the extent of their cognitive impairment.^{9,10} As such, nursing and other health professionals understand that as the condition progresses, the persona of the person with dementia may change giving rise to new behaviours and attitudes.⁸ The person-centred care approach may go some way to maximising the well-being of people with dementia⁸⁻¹⁰ by attending to the new experiences and interactions which are occurring in their lives. What is more, person-centred practices can also extend to family members, significant others and informal carers of the person with dementia.⁸

While the person-centred care approach is advocated in a plethora of healthcare literature, a universal definition is somewhat harder to define. Carl Rogers¹¹ provided seminal theory around the area of person-centred care some 75 years ago. Rogers' work was later applied to healthcare by Neuman and Young.¹² Importantly, person-centred care specifies that healthcare professionals should collaborate with patients and their families to encourage their participation in their care in order to come to best treatment decisions.¹³⁻¹⁶ Essentially, the patient-centred care approach seeks to prioritise healthcare professionals' communication styles, how shared decisions about treatment are made and the extent to which patients and their families feel empowered to engage in their healthcare.^{14,16}

Despite these best practices, it is still common for people with dementia to become distressed owing to the clinical manifestations of the disease.¹ The manifestation of distress, formally termed 'behaviour that challenges', may include anxiety, anger, depression, fear or suspicion and it is estimated that this occurs in around 60%–90% of people with dementia.^{17,18} While the work for curative and symptom-reducing treatments continues in the field, there has been a recent drive towards improving and enriching the lives of people with dementia, particularly around alleviating distress.⁹ Previously, distress was entirely managed by healthcare professionals through the use of medications such as risperidone and olanzapine.¹⁹ These particular medications are termed 'anti-psychotic' and are different to the 'anti-dementia' medications recommended in clinical practice, for example, galantamine and memantine, as these medications seek to slow the progress of the disease.^{9,19,20} While pharmacological intervention may be appropriate in certain circumstances for some people with dementia who are exhibiting signs of extreme distress, this approach may be considered by some as not particularly person-centred, or indeed best practice, to seek to manage distress by way of medications in the first instance.¹⁸ This may be due to personal preference and/or shared decision-making, yet it could be argued that aspects of building mutual respect and developing a therapeutic relationship with people who have dementia are neglected.^{21,22} Ethical considerations aside, the physical consequences of these medicines may include sedative effects, increased risk of falls and increased levels of cognitive decline.^{18,19}

Alternatively, there are a number of non-pharmacological therapies that have been utilised for people with dementia reporting varying degrees of effectiveness.²³⁻²⁶ Non-pharmacological treatments typically seek to enrich the lives and promote the well-being of people with dementia as well as reduce potential distress. In clinical practice, a variety of non-pharmacological techniques have proved successful including

reality orientation, reminiscence therapy, aromatherapy and music therapy.^{23–25} Notably, these types of non-pharmacological therapies are proactive, that is to say, they are not necessarily carried out solely as a result of distress. In an attempt to maximise the well-being of the person with dementia,^{23–25} which is paramount in the person-centred care approach,^{9,10} such therapies can be practised as part of a routine plan of care. While there are a number of therapeutic intervention options for nursing professionals to choose from with regard to non-pharmacological treatments, there are perhaps few as contentious as doll therapy.²⁶

Background

The practice of providing dolls to people with dementia is not a recent phenomenon, indeed there have been accounts of its use over a decade ago.^{27,28} Despite this, there has been limited rigorous empirical research carried out on the use of providing dolls to people with dementia and subsequently best practice guidelines currently do not exist.²⁶ While a plethora of anecdotal accounts on successful doll therapy interventions with people who have dementia pervade the literature, the first notable attempt to empirically study the phenomenon came from the Newcastle Challenging Behaviour Service (UK) in 2006/2007.^{29–31} The Newcastle Challenging Behaviour Service (UK) carried out three separate studies throughout a variety of healthcare settings in England. Collectively, these sought to observe how doll therapy was received by the person with dementia, the feelings of formal care staff providing the intervention and the impact on well-being from the perspective of the person with dementia.^{29–31}

The Newcastle Challenging Behaviour Service (UK) found that if people with dementia were given the choice of a doll or teddy bear, a resounding 93% of those engaging with the therapy preferred the doll.³⁰ It was also noted that care staff were unable to predict which people with dementia would favour engagement with dolls.³⁰ Another key finding emphasised that while some formal care professionals, including nurses, were initially sceptical about the therapy, this often changed once engagement began.²⁹ Scepticism about the therapy pertained to the notion that providing dolls to people with dementia was ‘babyish ... totally demeaning ... patronising’ and could serve to ‘confuse residents further’ (p. 442).²⁹ In spite of ethical concerns, the intervention proceeded and consistent with the majority of preceding anecdotal accounts, doll therapy was observed to have the potential to greatly improve the well-being of people with dementia.^{28,29} This benefit was reported in a number of other studies.^{30–33} Additional therapeutic gains of doll therapy for people with dementia included reduction in agitation or behaviour that challenges, a reduction in wandering, an increased number of opportunities to engage, a higher receptivity to interactions with other people, an improvement of dietary intake and a general visible increased well-being.^{26,28–33}

While there is some evidence to suggest that providing a doll to some people with dementia has the potential for considerable therapeutic gain, barriers for its use have also been identified. As already alluded to, there are no ‘best practice’ clinical guidelines on the use of doll therapy for people with dementia in the United Kingdom and globally.²⁶ So, even though there is some support for using dolls therapeutically for people with dementia that may improve their well-being, owing to varied styles of dolls used,^{29,31,34,35} nursing professionals face a challenge in determining which type of doll to use and how to use it effectively. Figure 1, the empathy doll, and Figure 2, the anatomically correct doll (reproduced with permissions) illustrate the two most common types of dolls used in therapeutic doll therapy for people with dementia. As yet, there has been no empirical research carried out regarding which style of doll has the largest therapeutic effect in clinical practice. In addition to issues around best practice, nursing professionals may also call into question the ethical underpinnings of doll therapy.

Doll therapy has been shown to improve the well-being of some people with dementia, evidenced through anecdotal and a limited number of empirical studies.^{28–35} Nursing professionals have an integral and complex role to play in relation to supporting the use of dolls as a therapeutic intervention for people with dementia. On the one hand, it is a therapy that has been practised throughout the United Kingdom,



Figure 1. Empathy doll.

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Australia, Japan and the United States for over a decade.²⁶ Yet, on the other hand, there is an absence of clear and robust best practice guidelines and arguably a lot of confusion about the application of psychological theory to explain how the phenomenon is conceptualised. While there is potential for these limitations to be addressed in the future, it could be argued that in spite of the potential for improvement in well-being for people with dementia, there are some ethical issues that may impede its practice. In the next sections of this article, the therapeutic use of dolls for people with dementia will be examined through the lenses of ‘bioethical practice’ (particularly in relation to beneficence, non-maleficence, veracity and autonomy) and the personhood model of Professor Tom Kitwood. The rationale for providing a dual perspective on this phenomenon is because bioethical principles typically underpin all nursing care while the work of Kitwood specifically takes into account the care of the person with dementia.

Ethical considerations

The practice of doll therapy, while in its infancy, has produced favourable results for some people with dementia.²⁶ From a utilitarian perspective, arguably therapeutic engagement with dolls should be promoted for people with dementia based on the principle of beneficence.^{36–38} Beneficence in this instance refers to the nursing professional taking action to promote the welfare of people in their care.³⁶ The concept of beneficence as related to doll therapy can extend to the positive person work of Kitwood. Positive interaction or positive person work is a means by which communication and well-being for people with dementia are



Figure 2. Anatomically correct doll.

Reproduced with the kind permission of the Alexander Doll Company.

promoted.¹⁰ In addition, positive person work identifies a number of interactions which are considered to be beneficial to people with dementia which include play, relaxation and facilitation. These concepts are all pertinent to doll therapy and may to some extent provide nursing professionals with a rationale to support for its use.

While there are many benefits associated with doll therapy, there are also challenges with regard to its use as some may believe it to be a demeaning practice to those living with dementia and their families.^{39,40} The most common theme of contention has been identified as treating people with dementia as though they are like children.^{26,39–42} While there is some support for facilitating play in dementia care, doll therapy has been criticised for opposing the person-centred approach by infantilising the person with dementia.^{9,10,39,40} Infantilisation is defined as treating a person in a patronising way or as a parent might treat their very young child.¹⁰ Notably, Kitwood¹⁰ identified a number of depersonalising tendencies that healthcare professionals routinely exhibited which resulted in undermining the personhood of people living with dementia.⁴³ These depersonalising tendencies were largely based on ignorance as healthcare professionals did not always recognise that the person with dementia was, as Kitwood¹⁰ termed, an agent who could make things happen in the world. Kitwood¹⁰ referred to these practices as malignant social psychology⁴³ based on stigmatisation rather than acts of purposeful cruelty.^{9,10} With reference to the use of doll therapy, Kitwood identified infantilisation as behaviour worthy of being referred to in his theory of malignant social psychology.

It should be noted that many authors attribute the theoretical underpinnings of doll therapy to the work of developmental psychology^{44–47} with a particular focus on the work of child psychologists.²⁶ These theoretical underpinnings arguably add weight to the claim that the application of doll therapy is child-like in nature. As already stated, a dichotomy exists whereby in one sense there may be potential for benevolent action (beneficence) consistent with Kitwood's¹⁰ positive person work; however, there is also a risk of labelling the act as malevolent (non-maleficence) or as doing harm by means of infantilising the older person with dementia. As person-centred care seeks to move away from infantilisation of the older person, a

key facet of malignant social psychology, this presents a dilemma for nursing professionals to deliberate when considering the use of dolls as a worthwhile therapy for dementia patients.^{9,10,41}

A further important area for ethical consideration is that of choice. The ideology of person-centred care in the health arena is founded on the notion that all human beings are worthy of respect regardless of their disability.^{10,36} The principle of autonomy relates to the freedom of a person to self-determine their own course of action.³⁸ In other words, the person with dementia should be free to choose and entitled to act on their preferences so long as these decisions and actions do not stand to violate or impinge upon the significant moral interests of others.^{36–38} Due to the advancing disease, people with dementia may not be able to maximise their previous level of autonomy, for example, choosing which medicines are most appropriate for their care.^{10,14,48} Yet despite this cognitive decline, people with dementia need to be supported to make non-complex decisions like what to choose to eat for dinner.¹⁰ Doll therapy is considered a non-complex decision as engagement or non-engagement is unlikely to cause physical harm to the person with dementia and/or others. Applying the principle of autonomy would indicate that if the person wishes to engage with a doll, they should be supported to do so. While it has been acknowledged that there are no robust clinical guidelines on how best to support doll therapy, recommendations based on studies carried out by the Newcastle Challenging Behaviour Service (UK) advise that a doll should be strategically placed for the person to access.⁴⁹ However, this recommendation overlooks those with mobility or sight problems and may not facilitate or empower some people with dementia to self-determine about engaging with dolls.

In addition, the concept of the ‘therapeutic lie’ has been growing in dementia care literature.^{50–52} A therapeutic lie is told to someone when it is believed to be in their best interest.⁵³ Like the phenomenon of doll therapy, the ‘therapeutic lie’ has divided opinion in healthcare.^{52,53} Significantly, the two may overlap when considering veracity with doll therapy. Veracity is about truth-telling and considered a key component of Kitwood’s work on positive person work. Conversely, lying to people with dementia is considered by Kitwood¹⁰ as treachery, an undesirable facet of his theory on malignant social psychology. The increasing realism of some dolls utilised in empirical research has presented occasions when people with dementia consider their dolls to be a real baby.^{26,29,30,33,35} Advocates of the use of dolls do not suggest that the therapy is presented as life-like, but some believe that if a person with dementia considers the doll to be a baby that healthcare professionals should not try to correct this notion and as such engage in a form of therapeutic lying.⁴¹ Minshull⁴² supports this notion and believes that non-correction should be seen as ‘An avoidance of an unnecessary truth rather than a lie’ (p. 36). According to Tuckett,⁵⁴ the therapeutic lie can be understood in the context of compassion and fulfilling a part of beneficence if it is in the best interests of the person with dementia and subsequently serves to promote their well-being. Despite the potential for beneficence, there are many who believe that veracity is an important component of dementia care as well as person-centred care.⁵⁵

While engaging with dolls may seem physically harmless, as evidenced, there have been indications to suggest it has the potential to divide ethical opinion.^{26,30–32} In this context of doll therapy and autonomy, nursing professionals may need to think about the process of informed consent.^{56,57} The process of obtaining informed consent is challenging when considering the person with advancing dementia. However, in spite of this challenge, it is appropriate to make an individualised nursing care plan for engagement of this therapy as effectiveness and/or engagement with this may change over time. As already mentioned, the person with dementia may lack cognitive capacity and be unable to make complex decisions about their care. In such circumstances, usually a family member and nursing professional will act as an advocate for the person with dementia where complex decisions are necessary, for example, when to begin taking additional food supplements with meals to reduce weight loss.⁴⁸ While doll therapy is not physically harmful, it may be troubling for family to witness, and as person-centred care also places an emphasis on care of patient’s relatives, it is recommended that they are involved in the decision-making process about doll therapy. In order to maintain appropriate professional conduct, it may be appropriate for nursing staff to gain written consent

for the continual practice of doll therapy from the patients' relatives. To date, there are no clinical recommendations on how best this could be achieved.

In addition to the potential for distress from family members who may perceive that doll therapy is undignified,³⁹⁻⁴¹ it has been shown that over-engagement with dolls can lead to fatigue and exhaustion¹⁸ for the person with dementia. In addition, this severe distress may occur if the person with dementia loses his or her doll or believes his or her doll has died.^{26,29-31} As demonstrated, the concept of person-centred care can be an ambiguous term for some nursing professionals;¹⁴ despite this, there are a shared set of values that are intrinsic to the approach. These values closely mirror the work of Kitwood¹⁰ and the ideology of positive person work for people with dementia. These values include getting to know the patient as a person, enabling the patient to engage in shared decision-making about treatments, therapies and lifestyle choices, providing information that is individually tailored to each person in order to assist in their participation of decision-making and supporting the person to carry out their decisions.^{9,58} While complex decision-making may be reduced for people with advancing dementia, selection of non-complex therapies should be encouraged and supported by nursing professionals. While nursing professionals may wish to encourage people with dementia to make their own autonomous decisions, they must also recognise that these decisions may have consequences.

For some people with dementia, therapeutic engagement with dolls can be beneficial to their general level of well-being; yet ethical contentions around the phenomenon continue to exist. As illustrated, doll therapy can assist people with dementia in communication, increase their levels of engagement with other people and reduce episodes of distress. Arguably beneficence is further reinforced when considered alongside personal autonomy were the person with dementia should be supported to make their own decision about a non-complex therapy involving dolls. While these principles of beneficence and autonomy are supported by Kitwood's positive person work and the concept of person-centred care, they may not automatically replace or counter non-maleficence and veracity. The stigmatisation of people engaging with dolls may have implications about how the person with dementia is treated, that is, like a child. This notion is contraindicated in person-centred care and the positive person work of Kitwood. Advocacy then becomes a consideration for nursing professionals caring for this vulnerable population. For nursing professionals, the dichotomous position relating to the phenomenon of doll therapy for people with dementia, as either advocacy or discouragement, can be supported through the ethos of person-centred care, positive person work and well-known bioethical principles.

Discussion

Healthcare professionals may be faced with particular ethical dilemmas that impact on how they think about and care for dementia patients who engage with dolls. The significance of ethical decision-making around this therapeutic technique is that currently there are no right or wrong solutions, no uniform responses that must be made, no guidelines or standards that can support and inform how nursing professionals reason about, act and react to the phenomenon.²⁶ How nursing professionals reach a shared, reasoned outcome when making ethical decisions is an important consideration, particularly when confronted with a situation for which they are unprepared, do not understand and lack training.^{26,34,35} Their abilities to reason around the dilemma are shaped and influenced by the interactions of numerous factors including personal beliefs, values, knowledge and experiences.³⁸ Consequently, how one conceptualises and defines what is 'ethical' and indeed 'unethical' may vary between individuals.³⁶⁻³⁸ In the dementia care arena, this may result in the person with dementia being viewed and treated differently depending on how the healthcare professionals reason and resolve their ethical dilemmas around doll therapy.²⁶

To conduct oneself ethically generally requires a nursing professional to treat others with respect, doing 'good' and causing no harm, based on their personal choice to do so.³⁴ Rights entitlements on the other hand

are not based on personal choices to be applied or not but are actual legal claims and internationally agreed standards that influence and determine the morality of the current social context.⁵⁹ In this sense, considering dementia patients as rights' holders might better empower healthcare professionals to resolve the aforementioned ethical tensions when managing persons with dementia and applying (or not) doll therapy. Regrettably, dementia patients' ability to claim and protect their rights may be compromised, exposing them to greater risk of abuse, violence, injury, neglect, maltreatment and exploitation.^{48,57,60} For this reason, changing attitudes towards people with dementia remains a fundamental responsibility and challenge for social and healthcare service providers.

Internationally, adoption of the World Programme for Action Concerning Disabled Persons⁶¹ paved the way for a new approach to raise awareness about the need to recognise and respect the rights of people with dementia. Applying the jurisprudence of The Convention on the Rights of Persons with Disabilities⁶² has advanced the international normative framework on disability greatly. Promoting a rights-based culture within dementia care may ensure high quality and uniform services that can support a greater understanding of a contentious yet potentially beneficial therapeutic technique like doll therapy. General principles of the convention pertinent to the phenomenon of doll therapy include 'respect for inherent dignity, individual autonomy, including the freedom to make one's own choices, and respect for differences and acceptance of others as part of human diversity' (Article 3). Interestingly, with regard to potential interventions, as outlined in Article 4 (f), State parties should

... undertake or promote research and development of universally designed goods, services, equipment and facilities, which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines ... [and] ... to promote the training of professionals and staff working with persons with disabilities so as to better provide the assistance and services guaranteed by those rights.

Finally, States also have an obligation to provide

appropriate measures to ensure their freedom of expression and opinion, and access to information through all forms of communication of their choice and accepting augmentative and alternative communication, and all other accessible means. (Article 21)⁶²

Doll therapy may be viewed as one such low-cost, easily accessible means that not only enables dementia patients to communicate and express their views but also has been shown to increase their well-being. Applying a rights-based approach can furnish healthcare professionals with an understanding on which to base their person-centred ethical decisions.

Conclusion

While there is much contention surrounding the practice of doll therapy, there is little doubt that some people with dementia benefit greatly from its use.^{48,63} The paucity of empirical research on its optimum utilisation in clinical practice, coupled with inconsistent practices and lack of guidelines, has led to a limited knowledge base among healthcare professionals about the phenomenon. As demonstrated through the multiple lenses of bioethics and the work of Kitwood, doll therapy can be viewed as either a positive or negative engagement. Irrespective of health professionals' understanding, they are duty-bound to keep the person with dementia at the core of their business. The principles of beneficence, non-maleficence, veracity, dignity and autonomy are fundamental values for nursing professionals in delivering holistic care for people with dementia. As demonstrated, a consensus on doll therapy for people with dementia is challenging for all facets of health professionals owing to the variety of interpretations illuminated in this article. The

challenge with this therapy is that it may be viewed by some as both beneficent (potential to increase personal well-being) and maleficent (potential to infantilise). This article argues that by applying a rights-based approach, compliant with the principles of the United Nations Convention on the Rights of Persons with Disabilities, provides an internationally agreed upon legal framework that considers dementia patients as 'rights holders' and encourages nursing professionals to place the dementia patient at the centre of their dilemma and to facilitate their personal choices where possible. In addition, those with responsibility towards caring for dementia patients have their capacity built to respect, protect and fulfil dementia patient's rights and needs.

Conflict of interest

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