

# Elderly disempowerment and do the means justify the end?

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## Introduction

Recently, we encountered a situation that highlights the fine line between doing a good deed yet potentially disempowering our older population. The aim of this paper is to promote healthy academic discussion regarding the various aspects of the situation including ethical, judicial, philosophical and other considerations. This is especially relevant to general practitioners (GPs) in New Zealand where aged care is becoming a priority.<sup>1</sup> It is predicted that the New Zealand population over 65 will increase from 600 000 in 2012 to 1.2 million in 2036.<sup>2</sup> We feel that this paper will allow for critical reflection resulting in more informed decisions should similar situations arise in the future. The identities of the people, by using fictitious names and contexts, have been anonymised. We also confirm that we were not involved in this person's clinical care.

The scenario relates to an older person, Bill, who had been finding it difficult to cope in his own home environment. He was told that he would be going on a 'short holiday' but in fact was being permanently relocated without his consent or wider family discussion. Bill was in his nineties, married to Jane and lived in a relatively remote and inaccessible property. He was experiencing cognitive decline and some physical impairment. However, he was very clear about his future goals including the wish to remain in his home until his death. His wife was also initially keen to stay on their isolated property. She was cognitively intact but also experiencing physical impairment. In addition, he had several hundred thousand dollars in his bank account and was the owner of prime real-estate (thus being both asset and cash rich).

## The dilemma

One day their daughter, Fiona, came for a visit from the opposite end of the country. She had not seen her parents for some time and was shocked by the condition they were in. She was most concerned about their inability to manage by themselves as they lived in a large house and the heating system had recently broken down. Fiona lived in a rural setting that was well resourced but more remote in comparison to where Bill and Jane resided. Although Bill wanted to remain on his property with the intention of making changes to their living arrangements, what ensued was a quick (over the weekend) decision by Fiona to relocate both her parents to where she lived; this decision was made without consulting her siblings or the extended family.

Jane agreed and decided it was the best solution for her but Bill did not want to go. A plan was then formulated by Fiona and within two days, she booked flights for the nearest airport to her home telling Bill that he was going on a 'short holiday'. Fiona took both her parents to the airport; neither of them had luggage, hence they left all their lifelong-acquired possessions back at their home. The siblings and close family members were told after the tickets had been purchased. Bill and Jane are now relocated; Jane is thriving but Bill has been experiencing severe cognitive deterioration. Of note, Bill's cognitive functioning was at this time not assessed by a geriatrician or a psychiatrist. We are not aware of any details regarding GP involvement.

In our opinion, due to the numerous issues involved in this case, the evidence does not easily

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**THIS ISSUE:** Ethical issues relating to increasingly common end of life decisions are discussed.

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translate into making a judgement in favour of either party, Fiona or Bill. The aim of this paper is to discuss the case from the perspective of Bill (the disempowered and vulnerable elderly person) with consideration of the difficulties faced by Fiona and other family members. The notion of vulnerability refers to people 'whose reserve capacity falls below the threshold needed to cope successfully with the challenges they face (p. 105)'.<sup>3</sup>

## Issues and considerations

### Truth-Telling

Truth Telling is an important process and concept that relates to how much information should be conveyed to the patient and family about their diagnosis and prognosis.<sup>4</sup> Truth-telling is associated with the issue of informed consent and the duty of health professionals to provide full and unencumbered information to patients with regard to discussing medical and healthcare options.<sup>5</sup> Truth-telling is particularly relevant to nurses and doctors who are directly involved with the care of their patient. There are several arguments about how much information should be conveyed. Tuckett<sup>4</sup> has debated these arguments under the headings of autonomy, physical and psychological benefits, intrinsic good and the uncertainty principle. We use this framework to further deliberate on this case.

### Autonomy

Autonomy implies self-determination and self-governance.<sup>4</sup> In our view, it is the right of every patient to be told about their condition and the treatment options available, so that they can make informed decisions regarding their future care. Older people are autonomous individuals and they are presumed to have decision-making capacity<sup>6</sup> until proven otherwise by a qualified health professional. In regards to capacity assessment, Darzins *et al.*<sup>7</sup> has outlined the six steps involved in this process and they are summarised in Table 1.

However, it is often a fine balance between protecting the rights, autonomy and safety of an individual when a family member has concerns that non-intervention may result in a reduced quality of life. If Bill had relinquished his position of autonomy due to his cognitive deterioration and his inability to make decisions that would optimise his care then Fiona may have some justification for withholding information, but the assumption here is that Bill no longer understands his predicament and is unable to contribute to a meaningful discussion about his own welfare.<sup>4</sup>

Fiona may feel she is protecting her father and is thus asserting the decision-making model of paternalism<sup>8</sup> to protect a vulnerable older person who lacks capacity. Her action is justified by the idea that she knows best for her father's health and wellbeing. This concept of paternalism is reliant on the patient being passive and on a judgment about (perceived) inability, lack of desire, or incapacity of the patient to engage actively in the treatment decision-making process.<sup>9</sup>

Loss of autonomy in this case is unclear, although there is a cloak of deception, because Bill has been relocated without any attempt to meaningfully discuss the issue of relocation with him or his other close family members. According to Tueth,<sup>10</sup> 'deception is intentional misrepresentation or concealment of information for a selfish motive (p. 106)'. In this case, Fiona had intentionally misrepresented or distorted the facts to Bill. Nonetheless, the motive for concealment is not obvious, and this would need to be investigated further to ascertain how Fiona had made such

Table 1. The six steps of capacity assessment

- Step 1: Perform capacity assessment only when there are valid triggers.
- Step 2: Find out from family members, health professionals, solicitors or financial advisors about the context in which decisions are to be taken.
- Step 3: Provide education to the person because ignorance can be mistaken for incapacity.
- Step 4: Involve the person because it is better to document that they are competent, or have some protection if their capacity is impaired.
- Step 5: Make conditions of examination as good as possible, for example exclude concurrent reversible illness and the person should be seen on his or her own to minimise coercion or undue influence.
- Step 6: Perform the assessment by determining whether the person can
  - (i) understand the relevant information; (ii) reason about treatment/management options; (iii) appreciate the situation and its consequences; and (iv) communicate a choice.

a decision. A further area of exploration would be to evaluate Bill's reaction to Fiona's option of moving as he may still retain some cognitive capability regarding his property and welfare.

Bill had adequate material resources available to him to realise his intention of continuing to stay in his home including close family, friends and money. These resources could have been used to enable access to good medical and nursing care and Bill had the means to make alterations to his present living conditions. While not currently frail, Bill may understandably deteriorate over time.<sup>11</sup> However, Bill's wish to remain in his own home was disregarded and not considered an option, with the consequence being a potentially detrimental effect on his psychological, cognitive and functional wellbeing. Bill has deteriorated significantly since leaving his home and no longer has the cognitive or physical capacity to access and utilise his resources. Although there is no evidence of overt coercion or intimidation, there is evidence that 'undue influence' was present in this case, especially given Bill's cognitive decline and his physical and mental vulnerability.<sup>2,3</sup>

Fiona's action may have come from a well intentioned perspective driven by the ethical principle of beneficence or distributive justice or the sense that the means used would be able to restore dignity and autonomy and therefore, the actions justify the ends.<sup>5</sup> Her justification may be consistent with the thinking along the lines of, 'Let's just give this new home a trial, you can come back home whenever you want to', which more often than not results in permanent relocation. Nonetheless, ageing in place could have been explored as a further possibility as it is often the preferred option for the elderly as it enables them to continue living in their own homes.<sup>12,13</sup>

### Physical benefits

Tuckett<sup>4</sup> reports that truthfully informing patients about their care options likely results in cooperation. One of the benefits of being honest is the act of compliance which has a beneficial corollary with reducing morbidity. The problem with not fully informing the patient is non-compliance to treatment, loss of trust and the advent of resentment.<sup>4,5</sup> Although truthful sharing of information

may bring direct physical benefits for the patient, it may also result in the development of caregiver burnout and distress, which may in turn result in reduced capacity to care for the patient.<sup>4,5</sup>

### Psychological benefits

Tuckett<sup>4</sup> poses that 'deceptive practices risk being discovered and mistrust results when patients eventually conclude that they are not being told the truth about their diagnosis or prognosis (p. 4)'. The risk in Bill's case is that he is aware of the changes regarding relocation and of the deception that occurred, whether it being meaningful or not.

If we assume that aspects of fear, distrust, pain, and anxiety can be alleviated through careful planning then the prospect of leaving all his memories behind could be alleviated. One of the concerns associated with this case is that leaving behind memories, both physical and emotional, for a person who is experiencing progressive cognitive decline may result in anxiety and confusion. Moreover, in his present residence with Fiona, Bill has minimal access to his support network, which includes other relatives and his old friends.

The options for moving Bill were complex given his cognitive decline and difficulties with maintaining independent care that impacted on his functional quality of life. Nonetheless, to ensure that Bill's intended goals regarding care are respected, discussions between key stakeholders together with Bill could have been considered in the decision-making process. Means<sup>14</sup> suggests that 'place attachment' needs to be acknowledged as an issue in this context, so that older people can keep their past connections alive. It is well documented that over time people build high levels of emotional attachment to their place of residence due to the meaningful memories that have developed.<sup>15</sup>

Two further aspects that need to be considered in the case of Bill that may justify the action of not revealing the truth, are the needs to reduce harm to self (including neglect) and to others. Deception in the case of Bill may be justified from the perspective of beneficence or acting to benefit others. If, for example, the relocation of Bill was considered in terms of his best interest,

fully informing him of Fiona's impending action could result in undue agitation, distress, and self-harm.<sup>4,5</sup> The decision being made can also be justified in terms of the benefits for Jane (for example, to reduce the stress as a carer for Bill). It is also possible that Fiona did not want to face the prospect of a difficult discussion with Bill whereby if Bill insisted on remaining in his own home that it might have contributed to further stress for both Jane and herself.

### Intrinsic good

Tuckett<sup>4</sup> proposes that within the framework of intrinsic good, truth-telling is consistent with recognised societal values, such as the duty and obligation to be honest. By removing this duty and obligation, Bill may become disempowered especially as he is entering a vulnerable period in his life. The action of deception is likely to leave him in a vulnerable position<sup>16</sup> and due to his vulnerable state the safeguards available for older people are likely not well known to him. Nonetheless, relocation as an outcome may be beneficial depending on how the new environment fits with Bill's needs.<sup>15</sup> There is evidence that satisfaction with new residential settings can be high, due to the functional advantages of moving into a well maintained new home.<sup>15</sup> We feel the issue of disempowerment in this case is not about the physical relocation of Bill, but about the lack of procedural justice, low engagement in meaningful discussion and misrepresented relocation promises.

### Uncertainty principle

Tuckett's<sup>4</sup> last consideration rests on the idea that disguising or not revealing the truth could be viewed as being acceptable if the diagnosis or future of the patient is uncertain. The argument in Fiona's case is that Bill's future may not be seen as certain and that with proper care and resources his state of mind and body could be better served away from his former residence in a house that is better suited to catering for his needs. There is an argument here that follows the logic, 'What is truth and reality?' Fiona's sense of truth is about intention to do 'good' against all odds. The notion of trust could be seen as a sense of grappling with uncertainty and the truth

becomes obscured by a personal sense of duty to care for one's father against the obligation of societal norms whereby truth must be adhered to at all times.<sup>5</sup> Trust is thus developed through caring and convincing Bill that the new situation is better than the previous set of conditions and time will be the healer of mistrust that may occur if Bill realises the initial deceptive scenario.

### Medico-Legal considerations

In New Zealand, there are legal implications to Bill's situation and there is a right of appeal because Bill may still retain the capacity to make decisions on his property and welfare or appoint an appropriate enduring power of attorney who will work in his best interest. Another issue relevant to this case is that disposal of assets should be directed by legal mandate as informed by a formal assessment of capacity. Legal representation needs to oversee the selling and disposal of assets and the owner (Bill or possibly jointly with Jane) has the right, if he has capacity, to be the mainstay regarding these decisions. If the issue of decision-making capacity has not been formally assessed the management of Bill's property and welfare will need to be considered under the appropriate legislation (*Protection of Personal and Property Rights Act*).<sup>17,18</sup>

Fiona's protection of Bill may have been motivated by changes to the *Crimes Act* introduced in 2012 to ensure that certain people are legally responsible for protecting a vulnerable adult from injury or neglect.<sup>19</sup> At home, anyone who is over 18 and who is aware that abuse of a vulnerable adult is occurring in the household they live in or are a member of (whether or not they live there) must take reasonable steps to protect that vulnerable adult from death, serious harm or sexual assault. In particular, caregivers of vulnerable adults must ensure that all their basic needs are met and take reasonable steps to protect them from injury. The maximum penalty for not taking reasonable steps to protect a vulnerable adult from injury or neglect is 10 years in prison.

Coercion of older people with cognitive impairment is not uncommon in our society and only rarely brought to the attention of health-care providers. In Bill's case, neither his spouse nor his daughter are likely to complain, and Bill himself was not in a position to do so. Age Concern

New Zealand, a non-governmental organisation, considers preventing choice or decision-making by an older person as a form of psychological abuse. Other family members or friends of Bill's who are seriously concerned about Fiona's actions have the option to refer the case to Age Concern's Elder Abuse and Neglect Prevention Services for further investigation.<sup>20</sup>

### Role of GPs

The transition from an autonomous to an incompetent older person can be difficult to detect, particularly if there is no reliable history or observation on such transition. It is likely that GPs may be involved in the assessment of people with both cognitive and physical decline and, therefore, their role is an important one and merits further exploration. As GPs are often familiar with the older people who have been on their caseloads for some time, they are well placed to understand their needs and that of their families. However, the requirement for cognitive or physical assessment usually arises only if and when a crisis emerges rather than being part of a routine assessment. We propose that further investigation into the efficacy of routine assessments be examined as they could be a part of an annual wellbeing check that will likely allow the monitoring of a pattern of decline.

However, as seen in Bill's case, when someone is unknown to a GP or not frequently seen, it is difficult to establish what a person's premorbid functioning or baseline was, and therefore the GP is reliant on collateral information from concerned family members, who, as mentioned above, largely act in the person's best interests but occasionally may be exerting undue influence. Therefore, consistent with Ageing in Place, integrated health and disability support services that are responsive and informed by the needs of older people, and which support them remaining in their own homes, should be first considered.<sup>21</sup> GPs are often at the centre of such community care coordination within the multiprofessional team.

When working with vulnerable older people, it is important to clarify what makes an older person feel vulnerable.<sup>22</sup> Vulnerability for an older person may represent an emotional response to particular situations as opposed to descriptors by healthcare

workers where the focus is usually on physical, psychological or social factors and factors related to care provision which do not usually consider these emotional responses. For example, in Bill's situation, not having access to his friends or other close relatives may render him feeling at the mercy of others and vulnerable as he is not able to leave home despite having adequate family support.

In New Zealand, Age Concern<sup>20</sup> has numerous local branches across the country catering to the needs of elderly people. It promotes elderly wellbeing and dignity while helping to address elder abuse and neglect. Older people and their families as well as GPs can access their resources and support from within their local communities. Hospital geriatricians and psychogeriatricians, who are familiar with the legal and ethical issues in the care of older people, are also well placed to provide advice to GPs when a complex situation is encountered.

### Conclusions

We have presented a difficult situation not infrequently encountered by GPs and the ethical issues associated with it. Tuckett<sup>4</sup> suggests that the underlying assumptions behind action need to be teased out and that health professionals can only come to terms with the true dynamics via therapeutic and informed communication. It is through this process that they can assist families and the vulnerable or those people marginalised in our society to come to terms with their preferred options. This paper will likely create ongoing debate and we feel this is a healthy way to proceed to ensure that our vulnerable elderly population are not disempowered.

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