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ABSTRACT

This paper explores several issues regarding the treatment and care for patients suffering from dementia, including a discussion of the relatively low time and money spent on dementia research compared to research on cancer and cardio-vascular diseases. It also discusses the special relationship between the person suffering from dementia and their caregiver, who is often a loved one. The paper employs principlism and so examines these issues from a consideration of autonomy, non-maleficence, beneficence, and justice.

Key Words: Autonomy, Non- Maleficence, Justice, Dementia, Disease Community

Note: This paper has been presented at the Nova Scotia Alzheimer's Society, Seaview Guest Home, and the Cape Breton Regional Hospital. Thanks to audience members for their perceptive and helpful questions and comments.

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INTRODUCTION

This paper explores several issues regarding the treatment and care for patients suffering from dementia, including a discussion of the relatively little time and money spent on dementia research compared to research on other diseases such as cancer and cardio-vascular diseases. It will also discuss the special relationship between the person suffering from dementia and their caregiver, who is often a loved one. The paper employs principlism and so examines these issues from a consideration of autonomy, non-maleficence, beneficence, and justice (Beauchamp and Childress, 2012).

Like many others, my interest in dementia arose because a loved one, my father, contracted the disease, which eventually killed him. Looking back, he probably had Alzheimer's long before it was diagnosed. Our family thought he was (merely) depressed, which of course he was, but his depression was actually an effect of the fact that he was beginning to lose his mind. Misdiagnoses, or late diagnoses of Alzheimer's and other forms of dementia is very common and arises in part because there is no good physiological test for dementia, which I will discuss further later in the paper.¹ Also common is the difficulty of watching a loved one deteriorate from dementia. Of course, seeing any loved one ill is difficult, but there is something uniquely disquieting about

¹ Fortunately, this situation may soon change as a group of researchers (Nakamura et al., 2018) have currently had great success in developing a blood test for early detection of Alzheimer's disease.

seeing someone become increasingly unable to think or remember clearly and, essentially, turn into someone else entirely.

Let me begin by setting out a caveat. I offer no definitive answers here. Ethics in general very rarely finds such answers, and this is particularly true of dementia I think both because of the nature of the disease, and because ethical reflection on dementia is still relatively new. In fact, in *Dementia: Ethical Issues*, to which my discussion owes a great deal, the Nuffield Council on Bioethics has said that “specific guidelines, rules, and laws have a particular but limited role to play: they may help to set a framework pointing to ways in which problems may be resolved but they can rarely provide a definitive answer to a specific dilemma.” This may sound disappointing, but I also suspect that for those who have loved and/or cared for someone with dementia, there is a clear truth in his or her claim. So much of the caregiver’s work here depends on judgment in a particular situation in the context of a particular person and the stage of their dementia at that particular time. Attempting to apply abstract rules outside of this context could be very counterproductive.

This raises the issue of the caregiver. Because of the nature of the disease, people with dementia require a lot of care, and family and friends in the home often provide this care. Any discussion of the ethical issues of treating people with dementia will have to pay close attention to these caregivers. When we do so, what we often find is that caregivers are rarely faced with the ‘big ticket’ ethical dilemmas we typically think of in ethical discussions – e.g., ‘is abortion morally permissible?’ ‘Should we have a one or two tier medical public health care system?’ Rather, their concerns are often ‘small’ by comparison and arise in mundane, everyday situations. E.g., ‘Is it okay to lock Joan in her bedroom while I slip out for 15 minutes to get groceries for supper?’ ‘Is it okay to lie to Jim and tell him the stove is not working when he wants to cook and I am afraid he will hurt himself?’ This does not mean that these ‘small’ issues are unimportant. In fact, quite the opposite is true. Moreover, dealing with these sorts of issues often gives rise to a great deal of moral distress and moral residue in caregivers – the feeling that they have been forced by circumstances to do things they are not completely comfortable doing (See Jameton, 1984 & Webster and Baylis, 2000). Given the symbiotic relationship between caregivers and cared for people with dementia, and the importance of the caregiver in the cared for one’s life, it is absolutely essential to take these sort of issues seriously and to provide as much support as we can for caregivers (as well as for the people they care for). We know, e.g., that moral distress in new nurses can lead to all sorts of problems – from them reducing their work hours or creating a new, ‘more hardened’ identity, to quitting the profession altogether (B. Kelly, 1986; B. Kelly, 1998). We must make certain that something similar doesn’t happen to caregivers of people with dementia.

There are hosts of ways in which one can conduct an ethical inquiry. In practical situations such as this, however, a necessary first step is to collect all the relevant facts. It is within the context set by these facts that ethical analysis can be productive. Since 1979, when Beauchamp and Childress first published *Principles of Biomedical Ethics*, principlism has often been used to investigate ethical issues in bioethics. Principlism is a pluralistic theory. That is, under this approach, decisions about ethical issues are made with reference to a number of basic moral principles rather than just one. Beauchamp and Childress suggest four such principles: autonomy, beneficence, non-maleficence, and

justice. I will follow them in applying these four principles to the situation of treating and caring for people with dementia.

PRINCIPLISM

Let me briefly explain these four principles before moving on to discuss some of the relevant facts of dementia. Autonomy literally means ‘self-legislating,’ and is based upon the power or capacity humans have to make free choices. In a biomedical context, respect for the principle of autonomy is made most explicit by the requirement that informed consent must be acquired for all medical interventions either from the person herself (when she is competent), or from a proxy (when she is not).

Beneficence and Non-maleficence are the opposite sides of the same coin. Non-maleficence requires, in the words of the Hippocratic Oath, that we do no harm while beneficence requires us actively to seek positive benefits for our patients.

Justice has both a formal and a substantive aspect. Formally, justice requires that equals be treated equally; i.e., that we do not engage in arbitrary discrimination against someone (based, e.g., on their medical condition, gender, etc.). Substantively, theories of justice can vary quite wildly in terms of the way in which societal benefits and costs are distributed, from strict egalitarianism (everyone gets exactly the same) to considerations of those who are most in need or those who have the ability to pay.

SOME FACTS ABOUT DEMENTIA

Obviously, this is a huge area, and I cannot do anything more than point to a few things that will be relevant to our ethical analysis.

- 1) Dementia is *not* simply equivalent to old age. Though a large proportion of people will develop some form of dementia if they live long enough, dementia also affects people who are under 65. For example, 200,000 Americans under 65 currently have some form of dementia (Alzheimer’s Association, 2017). Moreover, it will have very little or no affect on others who live well beyond normal life expectancy. This is important to remember because it saves us from brushing aside the notion that dementia is inevitable and that there is little or nothing to be done for people suffering from it. As I discuss in more detail below, keeping this fact in mind may help rectify some of the rationale for providing relatively miniscule amounts of research money on dementia.
- 2) Dementia is *not* ‘death that leaves the body behind’, as is often thought. Clearly, dementia is a horribly incapacitating disease, especially in its latter stages. But people with dementia, particularly in its milder forms or early stages, and even at its moderate or middle stage, can do a variety of things that they used to do. And even though they often have trouble articulating things, this does not mean that their brain is not functioning at all. Nor does it mean that someone with dementia can find no positive value in his or her life (Alzheimer’s Society of Canada, 2018).
- 3) A related point: People with dementia will experience their symptoms quite differently. We should not, therefore, lump all patients into a single category of ‘dementia patients’ and treat them all in the same manner. Some patients, e.g., will be able to participate much more fully in decisions, and find much more satisfaction in their lives than others.
- 4) There is currently no simple physiological test to determine the presence of a dementia. The best diagnostic tool for determining dementia is still a cognitive

- memory test. This is one reason why dementia is often not diagnosed as early as we would like. Moreover, some patients find the cognitive/memory test disheartening. As one patient put it: “They put me through the whole rigmarole, a four-hour test that I came out of feeling like a total idiot. You come out thinking, ‘Where am I? Who am I?’” (Nuffield Council on Bioethics, 2009, p. 11).
- 5) The social costs of dementia are staggering. A 2008 study published by the Canadian Alzheimer Society maintained that the direct costs of dementia in Canada at that time was \$8 billion while the total economic burden on dementia in Canada was almost \$15 billion. Astronomical as these figures are, if nothing significant happens, those costs are expected to rise to \$92 billion and \$152 billion respectively by 2038. These figures raise questions about our ability to pay for dementia care and how to do so efficiently and fairly (Canadian Alzheimer Society & RiskAnalytica, 2008).

AUTONOMY

As we have moved in the past generation away from a paternalistic model of the patient-physician relationship, autonomy has acquired greater and greater significance. In general, this has been a good thing. But with reference to people with dementia, the privileging of autonomy has caused tremendous difficulties because of competency issues. That is, we often assume that people with dementia cannot make decisions on their own any longer and so we as professional health care workers or as family caregivers make decisions for them based on *our* preferences. There needn't be any malicious intent here: indeed, we often make our decisions with the person's best interest firmly in mind. But we need to note a number of issues here.

First, denying someone his or her autonomy is typically a harm to that person, no matter if we are doing what we think is best. As noted by the Leeds, England Christian Council on Ageing, *Faith in Elderly People*: “We have noticed that it is too easily assumed by the decision makers in providing care (as well as generally) that people with dementia are incapable of making choices and taking decisions (which will have a great impact on their future well-being), thereby ‘de-humanizing’ them” (cited in Nuffield Council, 2009, p. 79).

Second, there are a number of ways to conceive of autonomy and some are better suited to the situation of dealing with people with dementia than others. As noted in a previous section, autonomy is literally the ability to be self-legislating. Typically, the emphasis is placed upon the ‘self’, i.e., one acting independently of others using reason as one's guide. Both the “independence” and the “rationality” criteria are problematic for people with dementia. But there are other notions of autonomy that don't make these criteria so central. In particular, some feminists have promoted the idea of “relational autonomy.” Working on some empirical work first carried out by Carol Gilligan, they have suggested that the traditional view of autonomy is a distinctly male view (Gilligan, 1986). When we compare the ways in which boys and girls develop, we see that while boys tend to prefer abstract principles and independence, girls tend to favor emotional commitment and concrete relationships. As a result, Gilligan and others have argued that emotions and relationships must be considered as an important part of our decision making capacity since we are who we are within the web of relationships we have – with family members, with colleagues, with friends, and so. Hence, we ought to think of autonomy within the context of our relationships with others (See, e.g., Sherwin, 2000).

This is essential in considering people with dementia for as their illness progresses, they become more and more dependent on others. But this doesn't mean that they have lost all autonomy interests. We have to re-conceptualize their choices, though, as ones that are made jointly. Obviously, this will have tremendous consequences for legal issues as well as moral ones, and all of this will have to be reexamined as we move forward. The Nuffield Council on Bioethics has suggested that however we move forward exactly, we must encourage people with dementia "to retain and express their sense of self, rather than simply being protected from harm or interference. In order to give this support it is necessary for those providing care to try to understand what the person with dementia is feeling, wanting and experiencing," although this will become increasingly more difficult as the dementia becomes more severe (Nuffield Council, 2009, p. 27). Hence, as rational capacity diminishes, we must give more weight to their emotional responses, e.g., "enabling them to pursue activities that they appear to enjoy even if they lack the capacity to make relevant decisions" (Nuffield Council, 2009, p. 27).

NON-MALEFICENCE/BENEFICENCE

It is one thing to say that we ought to do things not to harm and/or to benefit people; it's quite another to say what this entails, even on a general level. For example, we could consider well-being as having to do with a person's moment-to-moment experiences. On such an account, promoting maximum well-being or happiness would entail maximizing the number of such positive experiences, whatever they might turn out to be. On another account, we might think of human well-being as containing a number of things beyond one's immediate experience, and think, e.g., that a person's rational capacity and/or ability to act autonomously is an important ingredient in a life that is worth living. On this account, then, increasing well-being will involve decreasing cognitive impairment as a way of increasing autonomous capacity. Note, however, that there can be tensions between these two conceptions of well-being. Consider, e.g., a drug that increased mental capacity and hence autonomy but decreased a person's moment by moment experience by making him more aware of his illness. Juggling these sorts of tensions will require an empathetic awareness on the part of caregivers (Nuffield Council, 2009, p. 28).

Indeed, there often will be dilemmas faced in caring for people with dementia between letting a person do what she wants even though doing so presents some risk to her. As caregivers, we tend to think of safety first, and while this may be appropriate in many, perhaps most cases, we need also to realize that we must trade off these things. Just think of your own life. Do you always forgo activities that you desire and enjoy just because they present some additional risk? Of course in your case now, as a competent person, you are making that choice, and that is quite different than the case we are considering here for an incompetent person suffering with dementia. But even so, we can imagine that were we in their shoes, we wouldn't want safety – especially minimal increments of it – *always* to override everything else, including pleasure. One thing that considering the principles of autonomy, beneficence and non-maleficence bring into relief is that the life of the person with dementia is bound thoroughly with his caregivers, both professionals and family members. Indeed, I think some help can be found here in drawing an analogy between a lover and a caregiver. We can think of the creation of a loving couple as altering three basic components of the lovers: their well-being, their autonomy, and even their identity. In terms of well-being, the pains and pleasures of your loved one become part of your pains and pleasures. Your happiness is now

interdependent. And the ways in which you make decisions changes as well. You no longer make them in isolation; rather, decisions, or important ones at least, are made jointly. As a result of these two fundamental changes, your very identity is altered as well. This is not to say that your individual self is now completely subsumed within the new 'couple', since there will continue to be room for some independence, but your identities now overlap and merge in intricate and interesting ways (Nozick, 1989, pp. 68-86; Stewart, 2007). I think you can see how this might well extend to the relationship between caregiver and cared for, though of course there are important differences. But the analogy brings out the interdependence that occurs in both relationships. It also brings out the fact that the caregiver's well-being is fundamentally important to the well-being of the person with dementia being cared for. Hence, we need to look seriously at ways in which we can make the work of caregivers more satisfying and less stressful.

Interestingly, this raises issues of the sorts of research on dementia that are carried out. The first thing to note about this is that the amount of research money devoted to dementia is paltry when compared to research dollars spent on cancer, strokes and heart ailments. I'll come back to this in a moment when considering the principle of justice. I want now to focus on how the research money on dementia – paltry though it may be -- is distributed between various sorts of research. Most of it is spent on finding cures for dementia (or at least slowing its progression), such as pharmacological interventions. While I don't want to disparage such research, it's important to note that in all likelihood, such research will do nothing or very little for those suffering from dementia now – especially for those in the latter stages of the disease – nor for their caregivers. These groups would benefit much more from social science research, which investigated such areas as: the experience of living with dementia for both caregivers and those cared-for; the quality of life of people with dementia; social stigma and dementia; how best to educate caregivers; how to make buildings etc. more 'dementia friendly'; and cost effectiveness of alternative forms of support (Nuffield Council, 2009, pp. 129-130).

JUSTICE

As noted at the beginning of this paper, the formal principle of justice requires that equals be treated equally while substantive theories of justice deal with how societal benefits and burdens are distributed. There is evidence to support the claim that people suffering from dementia receive less support than people suffering from other ailments such as cancer. For example, people with dementia are less likely to have palliative care offered than people dying from cancer (H-K Huang, et al., 2017). And, according to the British Geriatrics Society, "the emphasis of resource allocation, prioritization, performance targets, research funding, education and training has all been skewed towards higher tech treatments and 'sexier' conditions such as cancer and ischaemic heart disease which affect younger people and away from the needs of older people with incurable long term conditions" (Quoted in Nuffield Council, 2009, p. 128). For example, and following up on our earlier discussion about research dollars, a survey in the UK "of research papers on long-term conditions published since 2002 demonstrated that while 23.5 per cent were concerned with cancer and 17.6 per cent with cardiovascular diseases, only 1.4 per cent focused on dementia... [and] a total of £32.4 million [was] spent in 2007-08 on dementia [from the Dept. of Health and Medical Research Council], compared with £248.2 million the same year on cancer (Kapp and Prince, 2007, p. xv).

Part of the problem here may have to do with the fact that dementia patients, especially when they are afflicted in the later phases of the disease, are mentally incompetent. This differentiates them from, say, end stage cancer patients who may well still be competent. This is an especially important issue with respect to “non-therapeutic” research; i.e., research that will not benefit the research subject him or herself though it may benefit others suffering from the same disease at some time in the future. Competent adults are of course allowed to engage in such research studies so long as they are adequately informed about the study (including that it will not benefit them), and are not coerced. But incompetent Alzheimer’s patients are not able to consent for themselves, and having others consent for them is deeply problematic. Ordinarily, proxy consent – where we are deciding for others – is much more restrictive than consenting for ourselves. Hence, e.g., though a Jehovah Witness can decline a blood transfusion for him or herself, if they are a competent adult, they cannot decline the same treatment for their children who are under the age of consent.

Barry Brown has argued that we can find ways to deal with this, though it requires some re-thinking, both about notions of autonomy and of well-being. Fortunately, both of these concepts have already been discussed above. Briefly, one idea is to think of autonomy in relational terms and to think in particular of the relationship (and good) between the patient/research subject and those people who are part of the same “disease community.” The second idea involves thinking of a good/valuable/happy life over a period of time, and not just as a transitory, moment-by-moment experience. As we shall see, these two ideas are actually related.

Concerns about doing research on human beings without their consent stemmed from the revelations of Nazi experiments on Jews and others. Hence, the first principle of the 1947 Nuremberg Code is that voluntary consent is essential. Of course, people with advanced stages of dementia are not competent to provide voluntary consent. Proxy decisions must therefore be made for them by others. As noted earlier, however, there are restrictions placed on proxy voters that do not exist for competent adults making decisions over themselves. This is what makes non-therapeutic research problematic for incompetent research subjects. The possibility Brown raises is whether we can overcome this by suggesting that while ‘the good’ of society as a whole is too wide a field to justify non therapeutic research in these circumstances, the good of one’s “disease community” may offer such justification. This follows, or is at least consistent with a relational view of autonomy. Brown writes: In one sense “of conceptualizing the relation between the individual and the group, the good in view is neither that of society as a whole nor that of a single individual. It involves the group of persons with a condition, such as Alzheimer’s disease” (Brown, 2012, pp.100-101). Brown continues by quoting John Finnis’ conception of the common good. It is not “the greatest good for the greatest number,” but a “set of conditions which enables the members of a community to attain for themselves reasonable objectives, or to realize reasonably for themselves, the value(s) for the sake of which they have reason to collaborate with each other (positively or negatively) in a community (Quoted in Brown, 2012, p. 101).

The second idea involves thinking of a person over a period of time. My father, for example, devoted a great deal of his time to volunteering, and a considerable amount of his self-worth and his very moral identity came from his sense of helping others. Indeed, so too was his happiness: he *enjoyed* helping others. Given the opportunity, my

father almost certainly would have volunteered for non-therapeutic research to help others suffering from Alzheimer's, either now or in the future. Of course, it would be best to make wishes such as this formalized while the person is still competent. And health care institutions have to begin investigating the possibility of getting a (competent) patient's wishes on their charts in ways similar to procedures now common for indicating a patient's desire not to be resuscitated or to allow a "natural death." That such wishes are not formally known, however, should not preclude the possibility of proxy consent when such consent would be consistent with the character of the now incompetent person. Indeed, to deny this possibility seems somehow to diminish that person's autonomy and their happiness (considered over an extended period of time).

CONCLUDING REMARKS

There are obviously a number of issues that one could raise with respect to the ethics of caring for people with dementia. I have focused only on a few, and in particular have suggested that the best care of people with dementia may require slight shifts in our thinking about how best to conceive of autonomy, non-maleficence, beneficence, and justice in relation to this care.

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