



Situating dementia in the experience of old age: Reconstructing legal response

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ARTICLE INFO

Keywords:

Law
Dementia
Substitute decision making
Supported decision making
Mental capacity
Vulnerability

ABSTRACT

This paper examines the intersection of dementia with the physiological processes and social contexts of old age; assesses the current legal response to problems arising through that intersection; and considers the potentially transformative effect of re-thinking legal response with those contextualised problems in mind. Two distinctive problems are identified: a heightened risk of exploitation, and an increasingly intense need for care coinciding with a decreasing ability to recognise and respond to that need. These problems require a social (rather than medical) response, of which law is an integral part. Several areas of law (including adult guardianship, legislation and common law doctrine relating to health care consent/refusal, and the body of law relating to decision-making about agreements, transactions, and bequests) provide for that response through the medico-legal construct of mental capacity. This legal idea of mental capacity has survived extensive critique, particularly in relation to interpretation and implementation of Article 12 of the *Convention on the Rights of Persons With Disabilities*. The survival of the mental capacity construct can be attributed to its usefulness as a theoretical mechanism that provides both a justification for over-ruling choice and preference (locating autonomy in the mentally capable decision) and a process for doing so (the mental capacity assessment and determination). This ambit of usefulness is particularly relevant to the problems (arising in the context of dementia in old age) identified in this paper. Both problems engage the public interest, together with the fundamental legal principle of fairness, in ways that call for legal response of some kind. Supported decision-making, as the suggested replacement for mental capacity based legal response, applies awkwardly in these contexts; as far as the individual is concerned, her decision *has* been made (and she does not need assistance in making one). This paper concludes that the mental capacity construct is problematic both for the reasons identified in the CRPD discourse (in which the experience of dementia in old age has been largely invisible) and because of the complicated intersections between mental capacity, dementia, and old age. The paper concludes by setting out an alternative conceptual basis and framework for legal response, including over-ruling expressed choice and preference, constructed around a principled theory of vulnerability as an alternative to and replacement for the mental capacity construct.

1. Introduction

Old age is integral to the experience of dementia for most people, although the opposite is not true- dementia is not integral to the experience of old age. As observed by Seneca the Younger in the *Consolation ad Marciam*, (1 AD) “[t]here is not one type of old age for all people.” (Parkin, 2005). Between 90 and 98% of persons diagnosed with dementia *are* old, however, and the likelihood of developing dementia increases exponentially with age before plateauing around age 90 (Alzheimer's Society UK, Dementia UK, 2014; World Health Organization & Alzheimer's Disease International, 2012). This demography of dementia has two important implications. First, the numbers

of persons living with dementia in Canada and other industrialised nations is rising in accordance with aging populations. Second, the experience of dementia is, in the great majority of cases, the experience of dementia in old age.

The demography of dementia means that the physiological processes and social contexts of old age are integral to the experience of dementia for the great majority of persons. This contextualised experience of dementia gives rise to the distinctive problems identified and discussed in this paper: a heightened risk of exploitation, and an increasingly intense need for care coinciding with a decreasing ability to recognise and respond to that need. Both problems require a social response, of which law is an essential part. Responding to exploitation

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<https://doi.org/10.1016/j.ijlp.2019.101468>

Received 13 May 2019; Accepted 13 May 2019

Available online 17 July 2019

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requires disrupting exploitative relationships and/or setting aside transactions carried out by or (apparently) consented to by the person. Responding to a need for care that cannot be perceived or comprehended may be enabled through supported decision-making, but in many cases will require over-ruling a refusal of care (including, in the most extreme circumstances, care facility admission). In each context, the fundamental legal principle of autonomy is engaged in a way that requires legal justification and a clear and consistent basis and process for intervention.

The first part of this paper considers the intersection of dementia and the physiological processes and social contexts of old age, and how that intersection gives rise to the problems identified above. The second part examines the mental capacity construct as a theoretical mechanism in law that enables, justifies and provides a process for over-ruling choice and preference, followed by a discussion of the mental capacity critique in CRPD discourse and the identification of special problems arising through the intersection of mental capacity, old age and dementia. This paper concludes that the survival of the mental capacity construct in law, despite its conceptual difficulties, is attributable to the absence of a meaningful alternative, especially in relation to problems arising in the context of dementia in old age. The paper concludes by setting out an alternative model constructed on the basis of a principled theory of vulnerability.

2. Situating dementia in the experience of old age

Biological processes are at the roots of the many perplexing problems attendant on old age and of the methods of solving them, but the biological processes take place in economic, political and cultural contexts. They are inextricably interwoven with these contexts so that one reacts upon the other in all sorts of intricate ways. We need to know the ways in which social contexts react back into biological processes as well as to know the ways in which the biological processes condition social life (Dewey, 1939).

The term “old age” is used in this paper to refer to the deeply interconnected social contexts and physiological processes associated with aging beyond mid-life. No one turns old when they reach 65. The significance of 65 or any other chronological age is the socially agreed upon shorthand it provides for the point at which the experience of old age, for most people, begins. Old age in this sense (like childhood, middle-age, or young adulthood) is not a homogenous experience but is shaped by the many intersecting factors and identities that make up individual lives. At the same time (also like childhood), the physiological processes and social contexts of old age are distinctive in ways that give rise, in turn, to distinctive problems. The demography of dementia means that dementia is distinctive in this way.

The physiological nature of old age is one of change: physical changes, including decreasing physical strength; increasing vulnerability to disease; and (for some) changes in the performance of thinking processes, including the kind of changes identified/diagnosed as dementia. Dementia is defined by the World Health Organization as a “syndrome, usually of a chronic or progressive nature, in which there is deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from normal ageing.” (World Health Organization, 2016). Understanding the special nature of dementia is essential to understanding the way in which the experience of dementia in old age gives rise to the problems discussed in this paper and assessing the mental capacity construct as a basis for responding to those problems. First, the “ability to process thought” can be ascertained and measured only through an evaluation of the individual’s *performance* of thinking processes: judging, comprehending, remembering, and decision-making. In this way (and despite the “hard science” language of cognitive function) the diagnosis of dementia is a “matter of evaluative judgment,” more like an IQ test than a blood test:

At this most objective end of mental illness (that is, in the field of

“organic” dementias) it turns out there is no hard scientific boundary between disease and normality. Lines can be drawn, but their exact location is a matter of evaluative judgment based on correlations between neuro-pathology and symptoms and signs. But which symptoms and signs? How much forgetfulness is pathological? What counts as normal aging? (Hughes, Louw, & Sabat, 2005).

Alzheimer’s disease, stroke, vascular disease, or excessive alcohol use are all potential causes of dementia, but do not comprise “dementia” itself. The identification of cause is useful as a means of distinguishing dementia from remediable conditions such as delirium, but is otherwise not essential to the dementia diagnosis. Indeed, the underlying cause of dementia is more likely to remain theoretical during the individual’s life. Nor is the identification of one or more potential causal factors equivalent to a diagnosis of dementia. Development of a bio-medical test for Alzheimer’s disease will be important and useful in many ways but it will not provide a definitive bio-medical “dementia test” and finding a cure for Alzheimer’s disease will not cure dementia *per se*.

Second, unlike other forms of mental disorder (developmental disability, for example), dementia frequently involves a progressive, ongoing deterioration in the performance of thinking processes. Deterioration in this context refers both to the kinds of thinking processes impacted, becoming progressively more comprehensive, and to the extent of deviation “beyond what might be expected from normal aging.” This multi-faceted progression means that, as the experience of dementia changes, the problems arising through that experience will change accordingly. At the same time, evaluation of the “symptoms and signs” of dementia will become less ambiguous as the fluctuating shades of grey in the earlier stages of dementia give way to the black and white manifestation of advanced dementia (defined as a comprehensive and severe impairment in the performance of thinking processes).

The physiological changes associated with old age, including dementia, are experienced as “inextricably inter-woven” with multi-layered and intersecting social and relationship contexts. These contexts are both distinctive to old age and experienced in a way that is particular to each individual. The broad social context of old age is informed by a deeply engrained cultural ageism that constructs the visibly old as both sympathy-worthy and useless/irrelevant, even foolish. Ageism of this kind informs virtually all social interactions (from the doctor’s office to “micro” exchanges at the grocery store). At the same time, the “greedy geezer” meme rhetorically constructs the visibly old as wealthy beneficiaries of the postwar era, enjoying benefits and assets they don’t really “need” and don’t really deserve. This stereotype intersects with dramatically rising property values in many urban centres which have provided windfalls for older property owners while effectively shutting out younger generations. At the same time, individuals may be embedded in more specific community and/or cultural contexts that, while providing partial insulation from ageism in the general culture, may themselves be informed by harmful attitudes and stereotypes. More intimate still is each individual’s particular relationship contexts made up of family members and friends. The withdrawal from paid employment tends to consolidate the individual’s relationship contexts within the family, a shift that is further intensified as peers and same age family members decline and die. The older parent/adult child relationship, including the realignment of long established “family leader” roles and relationships of reliance, is a crucial and distinctive contextual constituent of old age for many (if not all) persons.

It is the intersection between these social contexts and the distinctive physiological processes of old age, in connection with the experience of dementia across the spectrum, that give rise to the distinctive problems identified in this paper: a heightened risk of exploitation, and an increasingly intense need for care coinciding with a decreasing ability to recognise and respond to that need. The

heightened risk of exploitation arises where the distortions of judgment characteristic of early to mid-stage dementia, when the individual is able to express choice and to plausibly perform formal processes and transactions (marriage, power of attorney appointment, gift-making, e.g.), intersect with changing family dynamics, increasing reliance on others, the co-existence of the greedy geezer and gullible easy mark stereotypes, and the intergenerational economic dynamic created by the escalation of property values and the shrinking middle class. The risk of exploitation may be absorbed, but can also be exacerbated by, the cultural/religious communities and/or personal relationships in which the individual is embedded. The most distinctive personal relationship associated with the experience of old age- the older parent/adult child relationship- is both the most common source of exploitation and the most important safeguard against it. The accumulation of assets and access to supports such as pensions is, similarly, a source of both strength/resilience and vulnerability in relation to exploitation. The second problem- an increasingly intense need for care coinciding with a decreasing ability to recognise and respond to that need- is more likely to develop as the “symptoms and signs” of dementia progress, a more comprehensively disordered performance of thinking processes that impacts both the person's performance of thinking processes (comprehending the necessity of eating for example) and her ability to carry out the functions through which those thoughts are put into action (purchasing, preparing, and eating food). These thinking problems are experienced in connection with generalised physiological changes (increasing frailty, vulnerability to disease) together with the symptoms of dementia's underlying cause.

The identification of a problem does not, in and of itself, call for or justify a social response to that problem. I contend that social response is justified in each of the problem-contexts identified above on the basis of fairness, as a fundamental principle of law, and on the basis of public policy. Provision of the necessary legal mechanisms through which exploitation is enabled- marriage, appointing powers of attorney, et al- without corresponding mechanisms for preventing/responding to exploitation is an abnegation of ethical responsibility, facilitating exploitation *contra* the interest of the public as well as the interests of the individual. Exploitation is by definition unfair, one person taking advantage of and benefitting from the vulnerability of another to that person's detriment. The equitable doctrines of equitable fraud, discussed in the following section, are rooted in this idea of fairness. The fairness principle is also engaged where the individual's increasingly intense need for care corresponds with a decreasing ability both to recognise and to respond that need (sometimes referred to as “cognitive” and “functional” capacity, respectively). Fairness in this context is inseparable from the idea of both justice and substantive equality: that it is discriminatory to treat an individual who cannot perceive and respond to her needs as if she could do so, and that injustice results from the failure to recognise and respond to that difference. This contextualised understanding of justice is informed by the concept of desert (Feinberg, 1999; Rawls, 1971), referring to damaging consequences that are *not* deserved and are, for this reason, both unjust and unfair.

3. Enabling social response: law and the mental capacity construct

Enabling social response will not require the involvement of law in every case. Law will always be required, however, where social response involves over-ruling a person's expressed will and preference. The “right to make personal decisions without interference by the state” was identified by the Supreme Court of Canada as “an aspect of the respect for human dignity on which the Charter is founded”, a “critical component of the right to liberty” and the “basic theory underlying the Charter, namely that the State will respect choices made by individuals and, to the greatest extent possible, will avoid subordinating those choices to any one conception of the good life.” (*R v Morgentaler*, [1988] 1 SCR 30 at 171). The “realization of personal autonomy and self-

determination,” together self-respect and self-worth, has also been described by the court as integral to dignity and equality before the law. (*Law v Canada (Minister of Employment and Immigration)*, [1999] 1 SCR 497 at para. 53) Persons can be mistaken about their interests (by deciding to act self-destructively, for example), or simply act “foolishly,” but that risk is a “correlative of liberty.... The dignity of the individual is at stake.” (Koch (Re) (1997), 35 OR (3d) 71 at 76 (Gen Div); *Starson v Swayze* 2003 SCC 32).

Supported decision-making, in contrast, requires only minimal legal involvement, if any. Because supportive decision-making does not contemplate or allow for over-ruling choice and preference (i.e. *substitute* decision-making) no legal mechanism is required beyond legislation facilitating the recognition of supported decisions by third parties, or providing a system and structure for enabling/supporting supported decision-making relationships.

Supported decision-making will provide the most appropriate response to problems arising from a person's disordered performance of thinking processes, including dementia, for most purposes. Supported decision-making is also the most consistent with the important legal principles discussed above, avoiding the autonomy-problems addressed by the problematic mental capacity construct discussed below. In relation to each of the distinctive problems identified in this paper, however, the nature of the problem makes supported decision-making a less apposite response; the individual has made her choice, and is actively resistant to the proposed alternative.

The law has traditionally provided for over-ruling expressed choice and preference in response to exploitation through common rules relating to mental capacity (incorporating the mental capacity construct described below) together with the doctrines of equitable fraud (undue influence and unconscionability). These rules/doctrines instruct professional third party actors not to effect transactions and agreements of different kinds (marriages, agreements, wills, gifts, etc.) unless they are satisfied that the individual is mentally capable of making the transaction or agreement in question, and that her or his decision to do so is “genuine” i.e. free from the undue influence and unconscionable manipulation by others. These rules also provide a mechanism through which transactions or agreements carried out in the past by persons who were not actually mentally capable at the time in question, or whose decision was not genuine, can be set aside. Adult protection legislation in several jurisdictions provides a different kind of response to *ongoing* exploitation (Montgomery et al., 2016). That response requires state actor intervention for the purposes of disrupting relationships of exploitation, a more serious threat to individual autonomy than setting aside *past* transactions at the request of the individual or her personal representative. Appointment of a guardian or admittance to a care facility may also be sought in response to exploitation, empowering substitute decision-maker to make decisions on behalf of the individual on a continuing, projected basis.

The second problem- an increasingly intense need for care coinciding with a decreasing ability to recognise and respond to that need- calls for a different kind of social response: the provision of services and care, of different kinds, to support the individual's well-being. That response requires the involvement of law only where providing care and services involves over-ruling the individual's expressed will and preference. Where this is the case, the provision of care and/or services may be effected through legislation applying to “self-neglect” (generally included within adult protection legislation); legislation applying to health care consent; adult guardianship legislation; and legislation enabling care facility admittance without consent.

With the exception of the equitable doctrines applying to exploitation, these legal responses allow for the individual's expression of choice and preference- to make a gift, for example, or refuse assistance/treatment- to be over-ruled where the person is found to be not “mentally capable” of making a decision about the matter in question. “Mental capacity” for this purpose refers to the cognitive process of decision making: understanding and appreciating the matter in

question; understanding and appreciating the consequences of deciding one way rather than another; weighing those consequences against one another in connection with one's own interests and priorities; making a decision and adopting it as one's "own." Cognition for this purpose refers to brain function i.e. the ability of the brain to carry out the processes of decision-making. This medico-legal construct of decision-making resolves the autonomy problem attendant on over-ruling choice by explaining the incapable person as non-autonomous: to be autonomous is to make personal decisions without interference (as an incident of both liberty and dignity); to be incapable of making decisions is to have no autonomy to interfere with (Hall, 2012). The idea of mental capacity as an objectively ascertainable "bio-fact" akin to a blood test is crucial to this theoretical resolution (Hall, 2012). The rhetorical construction of the mental capacity fact distances the assessment of mental capacity from the substantive content of the person's decisions (preserving her "right to be foolish"). Like cognitive function, however, decision-making ability can only be ascertained assessed through the performance of thinking processes, including both the conceptual and functional aspects of decision-making. The evaluation of decisions made, in relation to some measure, is a necessary part of that that assessment process.

Dementia is not synonymous with impaired mental capacity; a person's mental capacity can be impaired for many other reasons, and a diagnosis of dementia does not equate to an inability to make a particular kind of decision. Nevertheless, the significant overlap between the "symptoms and signs" of dementia and the indicia of impaired mental capacity means that dementia will always be relevant to the mental capacity question. Like the dementia diagnosis, the assessment of mental capacity is carried out through an evaluation of the person's performance of thinking processes as indicative of her or his ability to make a decision, despite the quasi-scientific rhetoric of the mental capacity construct and the "tools" through which it is assessed. A dementia diagnosis will always be relevant to the assessment of mental capacity for these reasons and the loss of decision-making ability in old age (determined through the evaluative process described above), after a long mentally capable adulthood, will generally be attributed to dementia.

The mental capacity construct in law has been subject to significant critique within the discourse surrounding the interpretation of Article 12 of the CRPD. The "authoritative if nor binding" interpretation (Martin et al., 2015) of Article 12 issued by the UN Committee on the Rights of Persons with Disabilities in General Comment #1 (*Convention on the Rights of Persons with Disabilities, General Comment #1*) describes mental capacity as "highly controversial", "not, as is commonly presented, an objective, scientific and naturally occurring phenomenon" but "contingent on social and political contexts, as are the disciplines, professions and practices which play a dominant role in assessing mental capacity." (CRPD General Comment No. 1 at para. 13). The General Comment interprets Article 12 as requiring the abolition of mental-capacity based laws that would enable the person's will and preference to be over-ruled by a substitute decision-maker. Leslie Salzman has described Article 12 as a "paradigm shift" through its creation of a "true presumption of legal capacity", calling for a "more nuanced approach towards determining decision-making status and greater reflection on how to assist an individual within the decision-making process." (Salzman, 2009). Kristin Booth Glen describes this new "paradigm" as "insist[ing] on the full legal capacity of every person with intellectual disabilities... do[ing] away with substituted decision-making in favour of society's obligation to provide appropriate supports to permit everyone to make his or her own decision" (as opposed to the "old idea of incapacity as an illness or defect that renders the person suffering it to an object of charity and protection, subject to plenary guardianship based on best interests which constrains her personal life and the control of her property.") (Booth Glen, 2012). Freeman et al., on the other hand, have argued that removal of mental capacity as a legally meaningful concept (and, therefore, substitute decision-making)

would effectively violate the rights of the cognitively impaired to enjoyment of the highest attainable standard of health, the right to liberty, and the right to justice (Freeman et al., 2015; Kayess and French, 2008). Peter Bartlett has suggested that the effectiveness of Article 12 is limited by its failure to provide an alternative method of evaluation that would determine when and what kinds of supports are necessary, and to consider situations where an individual rejects support that he or she objectively needs (Bartlett, 2012).

The CRPD discourse has been focused on the discriminatory impacts of mental capacity-based substitute decision-making for persons with developmental and intellectual disabilities: the discriminatory de facto identification of intellectual/developmental disability itself as equal to impaired decision-making capacity; the illusion of "substitute" decision making for persons never considered capable of decision making (making the guardian a replacement and not a substitute decision-maker); guardianship as an enforced, perpetual childhood precluding the development of autonomy, decision-making skills and psychological well-being; and the devastation caused by the death of parent-guardians for persons who have been deprived of the opportunity to develop those skills (Harmon, 1990; Gordon, 2000; Kohn, Blumenthal, & Campbell, 2013; Booth Glen, 2012; Bach & Kerzner, 2010). Special difficulties also arise through the intersection of the mental capacity construct with the experience of dementia in old age. Decision-making ability, like dementia, can be ascertained only through performance; the evaluation of that performance requires some kind of baseline or norm against which performance can be measured. For the older adult, that baseline is generally provided by her former (younger) self i.e. by the relationship of current decisions to the kinds of decisions the person made in the past. This identification of change with declining decision-making ability is problematic, constructing "normal" old age as a condition of non-change in which the old self resembles, as closely as possible, the (no longer existing) non-old self. Evaluating decision-making capacity in old age is further complicated by deeply rooted and pervasive social ageism which makes it more likely that visible signs of difference in old age (physical symptoms of disease and/or fragility e.g.) will be interpreted as pathological, while the physiological processes of aging create increased opportunities for examination and evaluation of the self by medical professionals and others. Paradoxically, the heavy stigma of dementia may make lawyers and other third party gatekeepers reluctant to find an older adult incapable of making a will, property transaction, or other legal instrument (by implication, because of concerns about dementia), even where concerns about exploitation are recognised (Benbow & Jolley, 2012; Werner & Doron, 2017).

Defence of the mental capacity construct has proceeded on the basis that some theoretically coherent explanation and mechanism for intervention is necessary, as opposed to ad hoc value-judgment based intervention, across the board paternalism vis a vis older adults, or the strict non-interventionism contemplated by the General Comment. If mental capacity is "contingent on social and political contexts" (including the social contexts of old age) in the "shifting sands" of early to mid stage dementia, objective value-neutral interpretation will be difficult if not impossible in many cases, increasing the likelihood that some other unacknowledged metric will be applied. Both paternalism and anti-paternalism (Kennedy, 1982) may therefore provide the de facto framework for interpretation; neither are consistent with the kind of principled, objective and consistent approach mental capacity purports to provide.

In the following section I set out an alternative framework for legal response based on, and justified by, the principled theory of vulnerability set out below.

4. After capacity: vulnerability as a basis for legal response

4.1. Vulnerability as vulnerabilities: definitions

The *Oxford English Dictionary* provides two definitions for the word

“vulnerable.” In the first, “vulnerable” is defined as “exposed to the possibility of being attacked or harmed, either physically or emotionally.” This idea of vulnerability resonates with Martha Fineman’s articulation of vulnerability as a “universal, inevitable and enduring aspect of the human condition.” (Fineman, 2008). Every human body is exposed to injury or illness—although some bodies are more exposed than others by reason of individual physiology and personality in connection with the social, economic, and relationship contexts in which each person is situated. Vulnerability is also a function of our nature as social beings. This social aspect of the vulnerable human condition” includes the “fundamental contradiction” identified by Duncan Kennedy: that the exercise of individual liberty is dependent on and can only be exercised in social context (Kennedy, 1976; Kennedy, 1982; Goldberg, 2012). This multi-dimensional human vulnerability manifests in different ways, at different points, for different people; while “undeniably universal, human vulnerability is also particular: it is experienced uniquely by each of us and this experience is greatly influenced by the quality and quantity of resources we possess or can command.” (Fineman, 2008) In the second definition, “vulnerable” refers to “a person in need of special care, support, or protection because of age, disability, or risk of abuse or neglect”. These members of “vulnerable populations” are defined in terms of their distinction from an invulnerable norm, an “adult liberal subject... stand[ing] not only outside of the passage of time, but also outside of human experience. [and] captur[ing] only one possible developmental stage—the least vulnerable— from among the many possible stages an actual individual might pass through if s/he lives a ‘normal’ lifespan.” (Fineman, 2008).

Both ideas of vulnerability are present within the law. The second idea of vulnerability underlies and justifies the (now limited) *parens patriae* jurisdiction: the idea that certain classes of persons are by definition vulnerable and therefore in need of protection. The vulnerability theory set out here as an alternative to the mental capacity construct is not a revival of *parens patriae* or the vulnerability construct on which it rests. The first idea of vulnerability as a universal condition that is experienced in different ways throughout the lifecourse, waxing and waning through the interaction of personal/individual and contextual/situational factors, resonates with the equitable theories of undue influence and unconscionability (Hall, 2008) and with the common law doctrines of negligence and necessity (Stapleton, 2003–2004). This idea of vulnerability, rooted in legal principles of fairness and justice, is considered and developed here as a theoretically coherent basis for legal response.

4.2. Vulnerability as a principled basis for legal response

The base-line or universal vulnerability flowing from our nature as social and embodied beings manifests in different ways for each individual depending on the individual’s physiological self, her social, material and relationship contexts, and the relationship between context and self. Individual vulnerability may therefore be increased by changes in the self and/or context throughout the life-course; vulnerabilities may also be absorbed, or resisted, by changes to the contexts in which the person is situated and/or through strengthening of the self. The baby, for example, is potentially highly vulnerable. Where the baby’s vulnerability is absorbed by a responsive and supportive (relationship, social and material) context, however, the baby’s vulnerability is significantly diminished to the extent that she or he is only marginally more vulnerable than most adults, and less vulnerable than some. Conversely, vulnerability can be significantly increased by contextual factors (poverty, social stigma, or abusive or oppressive relationship context, for example). Public responses to vulnerability must also take into account the potential for that response itself to increase vulnerability in unintended ways. Catriona Mackenzie, Wendy Rogers & Susan Dodd refer to this institutional source of vulnerability as “pathogenic”, “where the response intended to ameliorate vulnerability has

the paradoxical effect of exacerbating existing vulnerabilities or generating new ones.” (Mackenzie, Rogers, & Dodd, 2014).

Recognising a universal baseline of vulnerability does not equate to demanding its elimination; vulnerability can never be eliminated altogether and that is not the goal (although some universal social programs may be understood as lowering baseline vulnerability in a general sense). Social response to *heightened* vulnerability may be justified where that response works to recalibrate the relationship between context and self in a way that reduces vulnerability (without creating pathogenic consequences). The appropriate response will depend on the nature and source of heightened vulnerability in a particular case. In the case of the baby described above, for example, no response is required (although the baby is objectively a member of a “vulnerable population”). Where a baby’s material context cannot absorb her vulnerability, providing the baby’s family with housing and benefits may be one way to recalibrate the relationship between context and self in a way that reduces the baby’s vulnerability (although the baby’s physiological self remains unchanged). Where a baby’s vulnerability is otherwise absorbed by her context but a medical condition (for which treatment is available) creates heightened vulnerability, reducing that baby’s vulnerability requires treatment. In this last example, the baby’s vulnerability is reduced through strengthening her physiological self—her context remains the same. These simple examples show that heightened vulnerability arises in many different ways; that no single response will be appropriate in every case, and that the most appropriate response in the circumstances will depend on the nature of vulnerability and its source.

Bringing this vulnerability analysis to the problems discussed in the preceding sections constructs those problems in terms of a particular kind and quality of heightened vulnerability rather than impaired mental capacity or membership in a per se vulnerable group i.e. “persons with dementia.” This vulnerability arises where problems in the performance of thinking processes that cannot be ameliorated through strengthening the self (either through treatment or through assistance and support) create risks that are not absorbed by that person’s social and relationship contexts. The person with dementia whose potential vulnerability is absorbed by his or her social, material, and/or relationship context will therefore not be vulnerable in a sense requiring/justifying response; the degree of vulnerability experienced by the individual arises through the relationship between context and self. The objective of social response (including but not limited to legal response) is to reduce or deescalate heightened vulnerability by re-calibrating this relationship.

4.3. Responding to vulnerability: preliminary framework

The following section sets out a preliminary framework for evaluating vulnerability, for the purpose of determining whether social response is warranted for the purpose of reducing/de-escalating heightened vulnerability and, if warranted, for determining the appropriate response. This framework has been developed as a process for enabling response to the problems identified and discussed in this paper (problems arising through the experience of dementia in old age) without the legal mechanism of mental capacity. The framework is not limited to that context, although further contextualised work will be required to assess its potential application to other, contextualised problems. The process described in the framework may be initiated by a private actor (a person seeking to be appointed as a guardian e.g.) or by a public body such as the Public Guardian and Trustee; the outcome/response sought by that body will flow from the process findings established through the process described below.

Step 1: Evaluation of an individual’s conceptual and functional performance of thinking processes in relation to his or her management of finances and/or person using a reasonableness-based measure (likelihood or risk, gravity of risk, and understanding/adoption of risk), together with a consideration of relevant diagnosis and prognosis.

Evaluation of the person's performance of thinking processes would involve both conceptual and functional aspects of that performance (comprehension and judgment, for example, in addition to the ability to carry out thought through action). Evidence collected at this stage would include observations/interviews, collateral information, cognitive testing, and clinical observations. The measure of reasonableness reflects the articulation of evaluation at this step in terms of the individual's performance of thinking processes rather than "cognitive function." That articulation acknowledges and makes explicit the subject of assessment: X's evaluation of whether Ms. Y "can" understand is, in reality, an evaluation of the quality of understanding demonstrated by Ms. Y, and X's evaluation of whether Ms. Y "can" carry out the functions of independent daily living can only be an evaluation of whether or not Ms. Y's functioning is acceptable with reference to some standard or measure. The current absence of an *explicit* measure creates a meaning vacuum in which evaluators (whether legal or medical) apply their own measures on a covert, unregulated and inconsistent basis.

"Reasonableness" provides the appropriate measure at this stage because it is the objective legal test; legal objectivity is not the same as scientific objectivity, but nor is it subjective, and the measure it provides is both consistent and flexible (reasonableness = reasonable under the circumstances). Use of the legal standard reflects the legal nature of process, including the outcomes it may entail, together with the impossibility of the "perfect capacitor" and the scientific proof it purports to provide (Kapp & Mossman, 1996). This distinctively legal idea of reasonableness is associated with the creation of reasonable risk, balancing the likelihood of harm created by problems in the performance of thinking processes against the gravity of that harm (should it materialise), the person's perception of that risk, and the person's "functional" ability to carry out actions that would reduce that risk. If a person's problems in the performance of thinking processes are not a source of unreasonable risk (as established through this measure), the Step 1 requirement will not be met and the inquiry will not proceed to Step 2. Note that risk is relevant at Step 1 as it relates to the reasonableness (or not) of the person's performance of thinking processes, i.e. whether that performance is itself a *source* of risk in a way that makes it unreasonable. If a person perceives risk and affirmatively undertakes it, risk is the consequence of that decision (and not the person's performance of thinking processes); the decision not to eat is different from an inability to perceive the significance of eating and/or to carry out the tasks associated with eating, for example.

Diagnosis and prognosis are considered at Step 1 of a vulnerability-based model because of their relevance to the question of appropriate *response*, not to the question of whether or not the person's performance of thinking processes falls outside the measure of reasonableness described above. Diagnosis and prognosis indicate whether treatment is available to strengthen performance, and whether the person's performance of thinking processes is expected to remain stable, to decline, or to improve. All of these factors are essential to the question of appropriate response. The appointment of a substitute decision-maker will be considered only where the individual's performance of thinking processes is evaluated as outside the reasonableness measure, and where diagnosis/prognosis suggests that the impairment of thinking processes is chronic and/or declining and cannot be significantly ameliorated.

Where a person's performance of thinking processes falls outside the measure of reasonableness at this step, he or she is *potentially* vulnerable in a way that justifies response. The next step involves an assessment of the individual's social, relationship and material contexts in connection with the evaluation of thinking processes carried out in Step 1. Where heightened vulnerability is not established at the second step, substitute decision-making (over-ruling the person's expressed will and preference) will not be justified.

Step 2: Evaluation of vulnerability arising from the interaction between the impaired self and social/relationship/material context.

Step 2 involves the evaluation of vulnerability, taking into account

the relationship between the individual (including evaluation of the performance of thinking processes at Step 1) and the social, material, and relationship contexts in which the individual is situated. The potential vulnerability established through the inquiry carried out at Step 1 may be absorbed, or exacerbated, by those contexts. If absorbed, the inquiry stops. If not absorbed, or exacerbated, heightened vulnerability is established. Step 3 considers the most appropriate response to that vulnerability; the evidence gathered in relation to thinking processes (at Step 1) and context (at Step 2) will inform decision-making at Step 3. The potential for pathogenic vulnerability must also be taken into account and weighed at this step.

Contextual factors relevant to evaluation at this step would include: information about the person's living situation (where, with whom, and on what basis i.e. ownership, rental, etc.); a financial and property "snapshot"; information about current systems in place for financial management and home/ personal care (formal or informal); information about any services (health or otherwise) being provided to the person; information from family members (or other persons similarly situated) regarding their availability and willingness to provide care and support; information regarding any complaints regarding financial abuse made to the Public Guardian and Trustee or similar body.

The problems of social ageism, stigma, and the pathologisation of the aging self will not, of course, magically disappear within a vulnerability model. These forces will, unfortunately, continue to impact the assessment of vulnerability, risk, and the performance of thinking processes, just as they currently impact the assessment of mental capacity or "decision-making ability" (the two terms synonymous). The vulnerability lens has the potential to lessen the impact of these factors, however, by removing the sole focus on the self and requiring a consideration of the self in relation to context. It is not just the older person who is the subject of scrutiny and judgment but, equally, the contexts of her life and the way those contexts can be changed to reduce vulnerability. The model set out here also requires a consideration of pathogenic outcomes as part of the decision-making process about guardianship and other forms of legal and non-legal response.

Step 3: Consideration by an inter-disciplinary guardianship tribunal of the most effective response, under the circumstances, for recalibrating the relationship between self and context in a way that reduces the vulnerability established at Step 2. Alternative tools considered at this step include non-legal tools such as home supports or medical treatment (as indicated by Step 1); supported/assisted decision-making; advance planning instruments; or care facility admission.

This determination would be based on the information collected through steps 1 and 2, and would most appropriately be carried out by an interdisciplinary tribunal (including representation from law, medicine and social work). The potential creation of "pathogenic vulnerability" arising from different responses would also be considered at this stage.

Step 4: If private guardianship (substitute decision-making) provides the most appropriate response, who is best suited to be guardian? What supports will they need to effectively carry out this task?

The consideration of who is best suited to be a guardian is currently an important part of contested guardianship processes. The personal and contextual evidence required by steps 1 and 2 would provide the basis for that consideration in both contested and uncontested guardianship cases. The second consideration at this step (supports needed to effectively carry out the guardianship task) is, I suggest, essential to the success of guardianship as a mechanism for reducing vulnerability. Despite the historical origins of guardianship in public responsibility, our society has agreed that the functions of guardianship should be downloaded to private individuals wherever possible (through advance planning, court appointed guardianship, or other private arrangements). Fairness requires that these private (generally family-member) guardians be supported in carrying out that task. The inter-disciplinary guardianship tribunal structure outlined above would be capable of providing advice and information about a wide range of available

supports (although it could not provide them directly, or compel their provision).

The 4 steps set out in this model (including the evaluation of thinking processes) need not be carried out by physicians, with the exception of information regarding diagnosis and prognosis provided at Step 1 and medical representation on the proposed inter-disciplinary tribunal. The 2014 amendments to the statutory guardianship scheme in British Columbia (*Adult Guardianship Act 2.1*), enabling nurses, psychiatric nurses, occupational therapists, psychologists and social workers to become “qualified health providers” (for the purpose of carrying out one of the two stages in the statutory guardianship capacity assessment process) provides one template for identifying/qualifying professionals for the purpose of carrying out Steps 1 and 2 in the vulnerability based guardianship model set out above.

5. Conclusion

“One should stop worrying about whether what one believes is well grounded and start worrying about whether one has been imaginative enough to think up interesting alternatives to one’s present beliefs” (Rorty, 1999).

The de-contextualised medical model of dementia in popular discourse has constructed dementia as a bio-medical problem which, like diseases such as cancer or diabetes, is more frequently experienced in old age but has no more essential connection. That construction has in turn framed the proposed solutions (bio-medical research, treatment, and eventual cure) set out in the dementia strategies developed by Canada and other nations with aging populations. Contextualising dementia in the experience of old age I have identified two distinctive problems requiring a social rather than medical response, of which law is an essential element. The traditional legal approach to these problems, constructed around and justified by the medico-legal mental capacity construct (“decision-making ability” as objectively ascertainable brain function), is no longer sustainable. Abandoning the individual to the consequences of non-genuine decision making in the problem contexts discussed in this paper is inconsistent with fundamental legal principles of fairness and justice. In this paper I have set out an alternative approach that provides a transparent and consistent approach to assessing and responding to both embodied and social harm arising through the relationships between context and self. Responding to vulnerability acknowledges the importance of both autonomy and fairness as constituent parts of the complex legal value of dignity.

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