

RECONSTRUCTING VALUES AND
POLITICAL PREFERENCES:

**THE FAMILY CAREGIVER ROLE IN THE DECISION-MAKING PROCESS
OF THOSE AFFLICTED BY ACQUIRED BRAIN INJURY**



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ABSTRACT

As societies are ageing, the role of informal family caregiving is becoming increasingly crucial to the sustainability of long-term healthcare systems. Nonetheless, this vital role is typically undervalued. Similarly, the associated task of supported decision-making, which fall under the umbrella of caregiving, is often overlooked. This paper will report on a specific subset of family caregivers who care for a family member with acquired brain injury (ABI) - more commonly known as stroke survivors. These care recipients often suffer from impaired cognitive capacity and are thus in need of guidance in decision-making. The primary purpose of this research is to determine the ethical justification of the supported decision-making process of voting. Despite the need for assistance, this research will demonstrate that ABI-individuals should be included in the voting process. However, due to impaired ability to communicate, think, and learn, others may often be too quick to dismiss their decision-making capacity or discredit their judgment. Therefore, the goal of this thesis is to serve as ethical guidance on how the family caregiver should approach the supported decision-making process of voting and how to reconstruct values and political preferences to reach a shared and informed political decision. My research reflects a relational approach to supported decision-making and will illustrate that the family caregiver has an ethical responsibility to engage with the care recipient by not only incorporating and acting upon pre-stroke values, but also including post-stroke values to ensure that their voice is adequately represented in the political decision. In particular, this thesis argues that the caregiver should follow the moral criteria of placing the emphasis on respecting the dignity of the current self, instead of solely focusing on the autonomous person who one was prior to the affliction of brain damage. In doing so, post-stroke values should be included in the supported voting process.

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INTRODUCTION

PREFACE

As populations are ageing at unprecedented pace, so are the burdens on healthcare systems. In these ageing societies, the informal family caregiving role is often the backbone of long-term care systems. Nonetheless, this pivotal role is typically invisible and undervalued. In comparison to professional healthcare workers, informal family caregivers are individuals who provide unpaid care and assistance to a family member. A recent study conducted by the Dutch Institute for Social Research (SCP), a government agency, found that approximately five million people currently provide informal family care in the Netherlands alone (Ministry of Health, Welfare and Sport, 2020). The role of caregiving is multifaceted and, oftentimes, the extensive need for physical and psychological care overshadows the moral baggage which has covertly found its way onto the back of the caregiver.

To elaborate, this thesis paper will delve deeper into a specific subset of family caregivers, namely those who care for a family member with acquired brain injury (ABI). This umbrella term focuses on those who suffered brain damage after birth – either through traumatic or non-traumatic causes. A common form of ABI are strokes in which the brain function is acutely disrupted and alters how one's brain performs tasks. Within one year after having suffered a stroke, approximately 30% of stroke survivors develop an advanced form of dementia (Cullen et al., 2007). Both physical and cognitive deficits are most prevalent in the acute phase – i.e., directly after the onset of a stroke - cognitive impairment often persists and results in permanent disability in which the individual experiences social, physical, and cognitive dysfunction (Zulkifly et al., 2016).

While a stroke may strike abruptly, the road to recovery is arduous for both family and stroke victims. When viewed from a caregiver's perspective, the caring role does not solely involve helping out in the household, assisting with mobility or providing emotional support, it also entails constant reflection on the ethical appropriateness of certain decisions made with or on behalf of the family member as their capacity is severely impaired. Due to post-stroke cognitive impairment, the care recipient often needs assistance in decision-making. This, in turn, allocates the ethical responsibilities to the caregiver and, inevitably, one will encounter moral dilemmas in making ethical decisions on

behalf of their family member.

Notwithstanding, it is this appointed role of surrogate or supported decision-making to the family caregiver which is often overlooked and can range from trivial decisions – e.g., choosing what to have for dinner - to more significant decisions on, for example, who to vote for, organ donation, resuscitation in case of emergency, or nudging one into a healthier lifestyle – i.e., nutritional or therapeutic choices. However, it is in the decision-making process where the moral ambiguity often lies. To highlight one specific example, in the Netherlands, the individual is eligible for voting assistance. For example, postal and proxy voting is allowed when individuals are unable to visit the polling station themselves (Ministry of Foreign Affairs, 2021) or one is permitted to bring a, for example, family member to help cast their vote. However, even with the beforementioned provisions to complete their vote, stroke survivors may require further assistance. That is, in the decision on what to cast their vote. Questions may arise, such as: What are the care recipient's true political wants and needs, have values changed due to severe brain damage, which to prioritize, and how does the shift in decision-making authority impact the well-being of both the caregiver and the care recipient?

SCOPE

This thesis aims to answer ethical questions that confront informal family caregivers in real-life moral dilemmas which accompany the joint process of supported decision-making. To narrow down the scope, the emphasis will be placed on the practice of supported voting. That is, provisions to ensure that those with impaired cognitive capacity may participate in the voting process. Moreover, I will concentrate primarily on supported decision-making by informal family caregivers, as the extension to formal caregivers raises further questions beyond the scope of this thesis – e.g., how does having professional medical experience or being paid to provide care influence the decision-making process? Roughly sketched, this thesis will be structured as follows: Should cognitively impaired individuals be allowed to vote? If yes, should family members be allowed to help make decisions on what to vote for? If so, which values or moral criteria should be included in the supported decision-making process?

Furthermore, it is important to note that, in this thesis, the notion of supported voting has a twofold meaning: Assistance with (i) the *act* of voting – e.g., voting by proxy or

physical assistance – and (ii) the *process* of decision-making on who to vote for. Throughout the paper, this twofold nature of supported voting will be used interchangeably as assistance with both the *act* and *process* are required for the cognitively impaired individual to cast a vote – as will be portrayed later on in the case example. The emphasis, however, will be put on the ways in which decision-making assistance should be deployed by family caregivers aimed at those with impaired decisional capacity.

The research questions and central thesis of this project is as follows:

- i. Should supported voting for people with acquired brain injury be allowed?
- ii. If so, who is best equipped to assist in the voting process?
- iii. And which of their values, if any, should be included in the decision-making process?

In this thesis, I claim that those with acquired brain injuries should be allowed to vote despite the need for voting assistance. Moreover, I argue that family caregivers know the values and preferences of care recipients best. Therefore, while the task may be demanding, I argue that family caregivers should guide the supported voting process and include both pre- and post-stroke values in the ethical assessment of what to vote for.

The following chapters will further explain why the appointed role of family caregiving should be nurtured to help the care recipient on reaching an informed and values-based decision on what to cast their vote. This paper will thus argue in favor of assisted voting and determine the extent to which involvement in the decision-making process is ethically justified. However, before investigating which moral criteria may apply, it is important to examine the ethical complexity of surrogate and guided decision-making.

In chapter one, I will first provide the necessary theoretical background by discussing the relevant theories on alternate decision-making in the field of biomedical ethics. Here, I will differentiate between surrogate and supported decision-making within the healthcare context and how this is closely linked to the notion of autonomy. Subsequently, I will analyze how alternate decision-making applies to both caregivers and care recipients. I will further discuss how acquired brain injury can result in impaired decisional capacity and how this medical condition may shape the family caregiving role by drawing on literature from various frameworks of feminist ethics, commonly known as the ethics of care.

In chapter two, I will start out by asking the reader to envision a hypothetical case

example which will be frequently revisited throughout the course of the thesis. In the subsequent sections, I will discuss how alternate decision-making plays a role in the act of voting specifically for those with impaired decisional capacity. The following sections will scrutinize the ways in which these individuals should be allowed to vote and whether assisted voting is a viable solution. In these sections, I will provide arguments for and against disenfranchisement. Here, I will claim that capacity-based disenfranchisement is ethically impermissible, however, one should be wary of the influence of the supported voter.

In chapter three, I will analyze the justification of the commonly assigned role of informal caregiving to family members. Here, I will examine the moral appropriateness of assigning the supported decision-making role to family members and discuss how informal family caregiving and its associated task of supported voting may be regarded as overly demanding. Following this, I will argue that, despite the demanding task, shared family decision-making has mutual benefits for both the caregiver and the care recipient. I will conclude this chapter by arguing that family caregivers are best suited to conduct the decision-making process and examine the ethical limits and the degree to which caregiver involvement in political decision-making is permitted.

In chapter four, I will discuss the ways in which the family caregiver has an ethical responsibility to engage with the care recipient and include and act upon various values and principles to reach an informed decision on what to cast their vote. Here, I will differentiate between two value-categories of which I have termed *pre-values* – pre-stroke preferences and values - and *post-values* – post-stroke preferences and values - and investigate how the family caregiver should assess which values to incorporate and prioritize to reach an informed shared decision. Subsequently, I will examine how the notion of the authentic self is viewed by the caregiver and how it may affect the supported voting process. In reconstructing values and political preferences, I will argue that the focus should be on respect for dignity, rather than solely on respect for autonomy because of the importance to recognize and respect the new persona which may emerge after a stroke – even if this new self has limited autonomy. In the last section, I will claim that if the political choices are still inconclusive, the family caregiver is allowed to have the final say by basing the final decision on the best interest standard.

In the final chapter, I will provide an overall conclusion in which I will restate the thesis and reiterate the previously discussed key points. Lastly, I will highlight the main

contributions and limitations of this thesis and provide future recommendations for further research on supported decision-making and the ways in which the caregiver and those afflicted by acquired brain injury should play a role.

CHAPTER ONE: *BACKGROUND*

Before delving deeper into the ethical permissibility of assisted voting and the accompanying criteria in the forthcoming chapters, the first chapter will analyze the ways in which alternate decision-making occurs within the healthcare context. The following sections will differentiate between surrogate and supported decision-making and examine the ways in which these apply to specific situations. Following this, I will examine how the medical condition of acquired brain injury impacts decisional capacity. In the third section, I will dive deeper into the duty of informal family caregiving for those with acquired brain injuries, and, lastly, I will conclude this chapter with a brief summary.

LIMITATIONS OF AUTONOMY IN SURROGATE DECISION-MAKING

To begin, within the framework of healthcare decision-making, the concept of autonomy plays a vital role. In ethical terms, autonomy is about forming your own viewpoints and freely choose to act on one's own conception of the good life. However, the equivocal term is still heavily disputed within biomedical ethics. The most influential and continuously updated framework on the notion of respect for autonomy derives from Beauchamp and Childress' *Principles of Biomedical Ethics* (2019) in which they bring forward four pillars to guide moral reasoning in health professions. The first principle emphasizes that individuals should be respected and enabled to exercise their autonomy. That is, one should be free to act upon their own values, preferences, and beliefs and these autonomous choices are worthy of respect.

However, safeguarding autonomy has proven difficult when the patient is unable to explicitly express their choices and preferences. When individuals completely lack decision-making capacity, the ethical responsibility of decision-making is transferred to a health care proxy. It is in critical cases that one must rely on surrogates as they are simply incapable of making decisions and providing informed consent. However, in practice, there is no general consensus on the ways in which surrogate decision-making should be applied. Within the field of medical and bioethics, a considerable amount of literature can be found on surrogate decision-making by healthcare professionals on behalf of patients of those who lack capacity to make these decisions themselves (Dworkin, 1994; Asplund & Britton, 1989; Navin et al., 2021). With fully incompetent cases, healthcare professionals and one's

immediate family partake in shared decision-making on behalf of the patient. These healthcare decisions primarily center around ethical considerations of risks and benefits of specific treatments which could result in a fatal outcome. For instance, when prolonging life would result in a decline in one's quality of life and, thus, it is decided that one should be freed of physical and emotional discomfort. On this view, withholding or withdrawing life-sustaining treatment is justified.

To come to these decisions, the substitute judgment standard – which is based on the principle of respect for autonomy - is often invoked. To explain further, according to the American Medical Association (AMA) Code of Medical Ethics, “surrogate decision makers should base their decisions on the *substituted judgment standard*; in other words, they should use their knowledge of the patient's preferences and values to determine as best as possible what the patient would have decided herself” (Chaet, 2017, p.676). Another approach to surrogate decision-making is the *best interest standard* in which the surrogate decision need not necessarily rely on the values and preferences of a particular patient; rather, it is a more broad or objective view on what would be best for the patient (Johnston, 2012). Both standards are primarily invoked in the context of end-of-life medical decisions which are predominantly made by surrogate decision-makers on behalf of critically ill patients who lack decisional capacity (Vig et al., 2007). However, what, then, about non-medical decisions for those with impaired capacity in which the patient is not fully deprived of their cognitive capacity yet do need assistance in the decision-making process?

To recap, surrogate decision-making centers around making decisions on behalf of incompetent individuals and thus without including the care subjects in the decision-making process – i.e., without patient involvement. While the two beforementioned standards are primarily invoked in surrogate decision-making, these can also provide direction on how to guide the process of supported decision-making.

IMPAIRED CAPACITY AND SUPPORTED DECISION-MAKING

The above section has explained that surrogate decision-making is primarily done without patient involvement. Supported decision-making, however, revolves around interdependent decision-making between the care recipient and their family members. While surrogate decision-making is a feasible solution for those who suffered a total loss of capacity and for

end-of-life decisions, supported decision-making may be a more plausible solution for those with impaired cognitive capacity and for day-to-day decisions. In supported decision-making, the caregiver guides the decision-making process to help a care recipient make choices. That is, the collaborative process in which the proxy adequately accommodates those with impeded capacity to reach informed life decisions.

An example of individuals with limited capacity can be found in cases of acquired brain injury in which strokes are the most common type. While a loss in capacity can indeed be determined, the majority of stroke victims are not fully deprived of the ability to make decisions. Globally, this medical condition is a major cause of serious long-term neurological disability in adults as it severely compromises and destroys neural connections in the brain (Feigin et al., 2022). While physical effects quickly become apparent, mental properties or states such as changes in one's thinking, learning abilities, behavior and emotions will gradually surface after the brain resets and forms new neural pathways. Nevertheless, neural repair is limited and due to severely damaged cells and local brain function, progressive neurological impairment and changes in personality are oftentimes irreversible (Svensson et al., 2021).

After the acute medical phase has subsided and one is discharged from the hospital, a patient undergoes an extensive rehabilitation program to regain the highest possible level of autonomy and in which the aim is to increase self-reliance and learning to deal with mental and cognitive limitation, change, and loss. The first three months after the onset of a stroke are crucial for recovery (National Institutes of Health, 2021). However, it is in the period after rehabilitation – i.e., when the patient has returned to one's pre-stroke life and to the comfort of one's home – when the extent of the lasting effects as well as the degree to which the alteration of one's character or personality gradually becomes apparent. During this period, care services are distributed from healthcare professionals to informal (family) caregivers. In short, a shift occurs of ethical decision-making authority – ranging from minor decisions to ones which exceed their own capacities. Due to neurological impairment and the decline in information processing, it is often difficult to ascertain the morally appropriate ways in which decisions and choices should be taken. For example, how should one determine an adequate degree of assistance? Furthermore, one may quickly venture into the realm of surrogate decision-making as providing adequate assistance is a demanding task.

FAMILY CAREGIVING AND SUPPORTED DECISION-MAKING

Having examined the distinction between surrogate and supported decision-making and the impact of ABI on decision-making capacity, it is now necessary to investigate the difficulties which may arise when a family caregiver assumes responsibility for the supported decision-making process. Evidently, an ABI can have an immense impact upon not only the patient, but also onto other members of the family. For both the caregiver and care recipient, it is a long road to a new normal. To navigate this treacherous terrain, the supported decision-making approach may prove useful to maintain a moral balance. However, while striving towards supported decision-making in which the caregiver and the care recipient both contribute to reach an informed decision could provide a plausible point of departure to safeguard autonomy and self-determination, it is not without its own ethical challenges and the practical application often falls behind.

To elaborate further, stroke survivors are often limited in their capacity to fully or coherently express their will and preferences. Common conditions resulting from ABI are, for example, paralysis, speech impediment, and problems with balance and coordination. Moreover, it can influence one's ability to speak, understand, and express language. Thus, making the decision-making process strenuous and difficult.

Additionally, a different personality can emerge in cases of severe brain damage in which one could portray certain personality changes such as apathy, neglect, and impulsiveness (American Stroke Association, 2021). To exemplify, where a father once showed sincere interest, pride, and gratitude towards his child, this attitude is now replaced by indifference or simpler emotions – thus, lacking fatherly emotions. Such instances inadvertently shift the family dynamics and the relationships between family members – i.e., one's role within the family structure. In their study, Trygged, Hedlund and Kåreholt (2011) found that a stroke greatly increases the risk of divorce or separation compared to nonaffected individuals. Most separations occur within one year after a stroke has occurred. In other words, alterations in personality and behavior plays a significant role in exerting a strain on family relationships (Mukherjee et al., 2006).

On top of this, glances of the old self intertwined with new post-stroke personality traits fuels the confusion as to pinpoint to what extent the old self ceases to exist, and the new self emerges. To explain further, if current preferences remain unclear, one is quickly

enticed to revert and build upon previously known values and preferences. However, strokes cause alterations in identity and personality which, in turn, may result in emergence of new values. Therefore, the prior and current values – i.e., pre- and poststroke - could potentially conflict when one merely relies on the substituted judgment standard. In other words, the incongruity lies in the fact that both the expressed will or preferences in the present and previously expressed values are heavily enmeshed. Therefore, to come to a moral agreement, the caregiver has to continuously reflect, initiate, and frequently revisit conversations on various topics to ensure that the care recipient's autonomy, desires and interests are respected. This, however, is a heavy burden for the family caregiver to take on.

Furthermore, taking on the task of informal family caregiving is not only providing for the physical and emotional needs of the family member, an extensive array of ethical responsibilities and social challenges are associated with it. As a stroke suddenly strikes, caregivers find and feel themselves ill-prepared in taking on this new caring role (Smith et al., 2004). Both moral and care responsibilities are heavy burdens for family caregivers to take on, and, consequently, the caring role often minimizes one's physical and mental well-being (van Heugten et al., 2006). Within the social context, providing informal family care often results in opportunity costs and burdens and opportunities are oftentimes unequally distributed amongst family members (Gilligan, 2016; Anderson, 1999). In short, group-based inequalities exist between individuals within social groups. Structural inequality could therefore inadvertently impose the caregiving role to those lower ranked in social status and limit their opportunities to achieve well-being (Young, 2008). As research has shown, informal family caregiving perpetuates socioeconomic inequalities (van Groenou, 2020). Put differently, while the culturally appointed roles of caregiving may indeed offer many social benefits and thus should be nurtured, it is important to be wary of how the role of the family caregiver may be perceived as burdensome and disrupts the lives of those who provide care.

CONCLUSION

In this chapter, I laid down the groundwork for the chapters to follow. In the first section, I analyzed the ways in which surrogate decision-making is most commonly directed for the critically ill in which one is fully deprived of decisional capacity. In the subsequent section, I

shifted from medical to non-medical decision-making in cases of ABI - more specifically, stroke survivors - in which one suffers from impaired or limited decisional capacity. For these latter cases, I argue in favor of supported decision-making. While I claim that a collaborative process to reach informed life decisions should be the ideal standard, it is important to keep in mind that the duty of supported decision-making could be perceived as burdensome. In short, the goal of this chapter was to pave the way for a more detailed exploration of the supported voting process. That is, it is important to understand the ways in which brain damage impacts one's ability to make political decisions. Moreover, the heavy load of supported decision-making is often borne by a family caregiver who cares for a cognitively impaired relative and we should be wary of how the assigned task may disadvantage family caregivers because these burdens may ultimately affect their ability to adequately guide the supported voting process.

CHAPTER TWO: *THE RIGHT TO VOTE*

Before we can explore who is best suited to guide and which personal values to include in the assisted voting process, we must first settle the preliminary question whether those with impaired capacity to make decisions should be allowed to vote at all. In other words, if a person is no longer capable to explicitly express their thoughts, opinions, and beliefs, should they be allowed to participate in political processes? In the first section, I will briefly discuss how certain individuals and social groups are denied the right to vote. In the second section, I will provide a case example of filial caregiving to narrow down the scope. This case will be revisited throughout the course of this thesis. The third section will examine whether voter disenfranchisement – i.e., restriction of the right to vote - on grounds of cognitive deficits is morally defensible. This section will center around the view that those who are cognitively impaired cannot be trusted with the privilege or responsibility of voting and should, therefore, be prevented from exercising their right to vote to ensure fair elections. In the next section, however, I will counter this by arguing that exclusion of these individuals and groups of people engenders political and social inequality. Here, I will further provide additional counterarguments against disenfranchisement to illustrate how inclusion of such individuals or groups of people have political, moral and symbolic value. Lastly, I will conclude this chapter with a brief summary.

BOUNDARIES OF THE DEMOS

The question of who counts as part of the demos is a long-standing issue. Significant portions of populations have long been denied voting rights, and, currently, many are still barred from exercising their right to participate in the political process (Marshall, 2017). This form of democratic exclusion is called disenfranchisement in which certain groups of people are denied the right to a vote. A common example of this is age-based disenfranchisement in which children are restricted from voting until they reach a certain age, other disenfranchised groups might be those convicted of felonies or noncitizen residents (López-Guerra, 2014). However, the ways in which democratic inclusion should be assessed is still heavily debated.

One way to approach the assessment of democratic inclusion is by examining the question of who is affected by political decisions. For example, all those affected by a

collective decision should have a right to participate into making it (Dahl, 1990; Goodin, 2007; Song, 2012). In other words, one should be able to participate in political choices which govern one's life. Thus, democratic inclusion is expanded to all individuals as all citizens are ultimately affected by political decisions. However, if we were to follow this line of reasoning, how should we ascertain who are affected by political decisions? Moreover, to which species or space in time do we draw the line of being affected? As Goodin also acknowledges in his paper, it "would mean giving virtually everyone everywhere a vote on virtually everything decided anywhere" (2007, p.68).

In response, one could therefore argue that a certain degree of exclusion is justified to maintain democratic equilibrium. However, on which grounds should this be based? To narrow down the scope, this thesis will center around a specific form of democratic exclusion, namely, capacity-based disenfranchisement. In many democratic societies, the legal possibility of invoking voting rights of those who are cognitively impaired differs across states and countries and is linked in national legislation to legal capacity (Okwerekwu et al., 2018). However, the ambiguity lies in its immeasurableness. There exists great disparity on how capacity is assessed, and viewpoints vary immensely on the extent to which cognitive capacity is needed to vote. In short, it is difficult to assess whether an individual can sufficiently make an informed decision on voting. We could therefore question the following: Where do we set the threshold of incompetence? And at which neurological disorder do we draw the definitive line?

In the upcoming sections, I will discuss the following question: Should those with limited capacity to make decisions be allowed to vote? Before moving on to the discussion, it should be noted that limited capacity covers a wide array of individuals. As stated in the previous chapter, losses of brain functioning differs per individual as specific symptoms arise depending on which brain areas are affected and the consequences can range from moderate to severe physical and mental impairment. Therefore, to make it more tangible, I will first provide a case example.

CASE EXAMPLE

The following weeks after your father has suffered a severe stroke, you are primarily focused on to what extent he is able to relearn lost skills. Even though the stroke has left

him partially paralyzed and unable to speak coherently, small increases in speech, balance and coordination feel like giant leaps of progress. During this period, you decide to become his primary caregiver to ensure he can remain somewhat independent by living at home instead of a care facility. When he finally returns home after months of rehabilitation, an illusion of normalcy ensues. After the tumultuous period of extreme fatigue has steadily subsided and you both have adjusted to this new situation, the lasting effects of a stroke gradually unveils itself. At this point, you realize that while you are still biologically a child to a parent; socially, however, the parental role has been passed onto you. It is now your responsibility to guide the process of ethical decision-making. However, it is difficult to ascertain what his true wants and needs are. The condition of aphasia affected his ability to communicate, write, and understand language. Therefore, he easily dismisses conversations. Over time, you learn to construct your own nonverbal language by communicating through gestures, mumbled intonations, and facial expressions. You learn to interpret his basic thoughts and emotions and found a way to communicate without expecting a verbal response. However, what is actually going on in his mind, you can never truly grasp. While he previously was an avid human rights advocate, his current apathetic attitude towards current detrimental societal events has left no trace of his former convictions. Prior to his stroke, you both were devoted vegetarians; now, you are requested to cook the traditional meat dishes, you know, his mother used to cook for him when he was young. At the same time, however, he still enjoys watching the same news channel together during dinner. In short, fleeting glances and values of the pre-stroke self are heavily intermingled with the post-stroke persona. Now, with the elections just around the corner, you two have a decision to make.

A CASE FOR DISENFRANCHISEMENT:

ENSURING FAIR ELECTIONS

In the abovementioned case example, it has become clear that your father cannot exercise his right to vote nor make informed political judgments without your assistance in the voting process. However, does this justify stripping him of his right to vote?

Firstly, an advocate of disenfranchisement on grounds of incapacity could argue that your father may lack knowledge of the current political landscape and thus his ability to

make a carefully thought-out decision may prove inadequate. In other words, his brain damage has severely eroded his cognitive ability to make reasoned judgments. While some individuals only need moderate support to cast a ballot – e.g., reminding one of the date or overcoming logistical obstacles by escorting them to the polling station – your father may need support in voting decision-making from start to finish due to this neurological disability. As the case example has shown, your father currently portrays an indifferent attitude towards public affairs and, at first glance, it seems he no longer has the capacity or an interest to engage with political content. Therefore, he appears to lack self-determination to vote for a specific party. Without your guidance, it is unlikely he will vote on his own accord or have the capacity to provide the information required. Even if he could meet the registration requirements and possesses the necessary abilities to complete the task of voting – albeit with your assistance - he may not sufficiently grasp the political issues to cast a meaningful ballot.

Moreover, if we were to follow this train of thought, one could further argue that those with cognitive impairments should be stripped of their voting rights because it provides a gateway to voter fraud (Sonnicksen, 2016, p.336). With regard to supported voting, the care recipient may be either unaware of how their proxy vote is used or that they are being manipulated into a specific political direction. Indeed, your intentions as the assisted voter may not be genuine. Who is to say that you will not use your father's vote for your own political advantage? This, in turn, may jeopardize the integrity of the electoral process (Karlwish, 2004). As elections may be decided by narrow margins, both practices of enfranchising and disenfranchising particular segments of the populations could be the deciding factor. As an example, in the Netherlands, approximately 645.900 individuals are afflicted by ABI, according to the National Institute for Public Health and the Environment (2017). Therefore, one might be inclined to argue the following: As the right to vote is of great political value and can have a great impact on society as a whole, barring certain individuals from voting is a means to maximize overall well-being and prevents fraudulent interference in democratic practices thus safeguarding fair and just suffrage.

I, however, argue that propagating the idea of disenfranchisement to ensure fair elections is ethically flawed. That is, disenfranchisement could have the opposite effect when we move away from the individual and focus on the social group. As human lifespans are increasing significantly within democratic societies, so are the substantial and growing

group of citizens who are afflicted by cognitive deficits. Therefore, on the collective level, overall well-being will in the end be less by excluding this vastly growing group. In other words, enfranchising this cognitively impaired group will eventually be of political value as well. In short, when approached from fairness, one could argue that your father not only voices his own interests, his vote also represents the interests of a growing and vulnerable sector. Therefore, your father's right to vote benefits all members of the cognitively impaired community. Furthermore, I argue that the claim of providing a gateway to voter fraud is implausible because it assumes that people are in practice inclined to use the additional vote for their own political advantage. If this were indeed to be the case, this would mean that all the votes of individuals who cannot cast the ballot in person should be considered invalid as others have voted on their behalf. On this view, a vast majority of citizens should therefore be denied the right to vote and is not only limited to persons with cognitive disabilities. In the following sections, I will further build the case against disenfranchising those who lack cognitive capacity. By approaching it from the respect-based accounts for autonomy and dignity, I will argue that individuals with acquired brain injury should not be deprived of their voting rights.

A CASE AGAINST DISENFRANCHISEMENT:

ENSURING RESPECT FOR AUTONOMY

So far, I have argued that disenfranchisement of those with cognitive disabilities cannot be justified under the guise of fair elections. Instead of ensuring fairness, disenfranchisement could result in unjust distributions of opportunities and choices and can eventually tip the scale towards decreased societal well-being. In this section, I will further refute disenfranchisement of those with impaired decisional capacity by drawing on the respect-based account of autonomy.

In the previous section, it has been argued that a requisite for the right to vote is having the cognitive ability and political knowledge to arrive at reasoned political judgments. Following a long tradition in political theory, children are excluded from full citizenship on the ground of practical reasoning. The seventeenth century social philosopher John Locke insists that minors are malleable and first must develop their rational potential by enlightened ideas and reason (1989). According to Jean-Jacques Rousseau, as children

are still in the midst of developing reason, they are easily persuaded into political manipulation (1916). Immanuel Kant famously argued that children lack rational autonomy or self-legislation which are needed to resist irrational desire (2015). The same reasoning that voting requires the acquisition of reasoning and deliberating abilities is still applicable in contemporary democratic societies. That is, minors do not possess the relevant kind of autonomy needed to participate in political processes because their undeveloped brains prevent them from fully comprehending political rhetoric (Peto, 2020).

Correspondingly, a proponent of disenfranchisement could then state the following: Since minors lack this capacity and are therefore not allowed to vote until adolescents' cognitive capacity has reached adult levels, how is this disenfranchisement different from denying individuals with cognitive disabilities the right to vote? Put differently, if fully developed brains are a requisite and the lack of key reasoning abilities is regarded as a defensible criterion for disenfranchisement, why should it be different for adults with brain injury?

While this may be a plausible statement at first glance, I argue that this is an incomplete argument when looking at both the consequences and experiential evidence. To elaborate further, for children, exclusion from voting is only temporary. After having reached the voting age, one is allowed to participate in the political process. Whereas disenfranchisement for the latter group is permanent. Another significant discrepancy between both groups is that, in comparison to children, adults who have acquired a brain injury were previously and are partially still able to act upon their previously acquired autonomy. As Mráz rightfully puts it, "adult disenfranchisement is always about restricting rights that an individual already presumptively has, and it does not come with a presumptive promise of (re)enfranchisement. These circumstances express the inferior worth and unequal political status of adults who are deprived of their right to vote" (2020, p. 275).

In his work, philosopher Ronald Dworkin defends the moral authority of precedent autonomy – i.e., previous decisions and preferences formed prior to loss of cognitive functioning (1986, p.10). He argues that each individual has a right to respect for autonomy, even when individuals suffer from, for example, dementia. To achieve this, we should respect one's precedent autonomy. Put simply, respect for autonomy implies respect for precedent autonomy. On this view, to bar your father from voting is to undermine his

precedent autonomy. The civil right to vote is fundamentally connected to certain human rights – e.g., the right to freedom of opinion and expression (United Nations, 2021). Voting is a tool to empower citizens to express their will, beliefs, and preferences. Therefore, we could argue the following: By excluding your father from the opportunity to vote, he is both robbed of his prior and current voice and wishes.

Therefore, I claim that, while it may be true that your father is unable to make and act upon choices without some degree of involvement and support, he is not fully deprived from decisional capacity. According to the principle of respect for autonomy, one should be allowed and enabled to make their own choices and decisions (Beauchamp & Childress, 2019). Disenfranchisement, however, robs him of the ability to vote entirely and no longer giving the opportunity to act upon and discern his own political views. Therefore, I claim that voter disqualification of those who have impaired cognitive capacity hinders moral agency. That is, one is deprived of the capacity to act and the opportunity to make moral choices and decisions based on what he perceives to be right or wrong. In short, your father should not be disenfranchised because participation in the political process enables him to maximize his potential to become an active citizen.

ENSURING JUSTICE AND DIGNITY

In the previous section, I have argued that those with impaired cognitive capacity should be allowed to vote because they should be recognized as equal citizens and their autonomy should be respected. This section, however, will approach restriction of suffrage from the respect-based accounts of dignity and justice. Here, I will claim that disenfranchisement engenders political and social inequality. That is, it conveys the message that not all humans have a shared moral status and are recognized as equals (Schidel, 2022). Symbolically speaking, disenfranchisement could eradicate one's social status, increase social stratification, and could ultimately affect the treatment of persons with cognitive disabilities. To be more precise, lack of inclusion reflects negatively upon the social group and creates a sense of subordination (Scheffler, 2010).

Let us begin with the influential political theorist Iris Marion Young. In her work, she examines the concept of injustice by focusing on the recognition of social groups. Young suggests that “persons suffer injustice by virtue of structural inequality when their group

social positioning means that the operation of diverse institutions and practices conspire to limit their opportunities to achieve wellbeing” (2008, p.82). The practice of disenfranchisement is expressive and can shape thoughts, constructs meaning, and influence the opinions of people. In short, excluding particular social groups from political participation not only systematically disadvantages them, but also indirectly affirms the stigma related to cognitive disabilities. Moreover, the restriction of suffrage based on capacity-related ground may further perpetuate institutionalized inequalities.

Closely related to Young’s view on marginalization and stigmatization is the work of philosopher Martha Nussbaum on human dignity. First introduced by Amartya Sen in the 1980s, Nussbaum has written extensively on the actual capability – a set of available choices and opportunities - to achieve wellbeing. While significant analogies between the accounts of Sen and Nussbaum can be found in the ways in which they aim to improve well-being by examining capabilities of individuals, the frameworks differ in the ways in which Sen focuses mainly on enhancing individual freedom, whereas Nussbaum’s account revolves around respecting human dignity. Nussbaum further expands on the concept of human dignity by arguing that we should endorse a list of central valuable functionings (2003, p.41-42). Simply put, to lead a dignified life, one should be able to perform all ten central human capabilities. The tenth human capability is having control of one’s environment and is defined as follows: “Being able to participate effectively in political choices that govern one’s life; having the right of political participation, protections of free speech and association” (2003, p.42). According to Nussbaum, “to give some groups of people unequal voting rights [...] is to set them up in a position of subordination and indignity vis-à-vis others. It is to fail to recognize their equal human dignity” (2009, p.336). Therefore, disqualifying individuals from voting could potentially harm those who are already in socially vulnerable positions. Exclusion sends a clear message that one is unworthy of respect and that their social status is considered to be less than their fellow citizens.

If we were to apply this to our case, we could state that the act of voting strengthens your father’s sense of belonging, reinforces his sense of identity, and confirms his engagement in his community. Supported social relationships has shown to have significant effects on one’s psychological well-being and can help to prevent or halt further mental deterioration (Green et al., 2002). Therefore, voting is a means to improve his quality of life. However, when disenfranchised, he is entirely stripped from the potential to enhance his

personal wellbeing. In this vein, one could further argue that disenfranchisement provides a bleak outlook on improvement as being labeled incompetent could rapidly become a self-fulfilling prophecy (Pasman, 2011). Thus, instead of making progress in regaining his independence as well as his sense of belonging, your father could gradually deteriorate.

Besides the negative impact of exclusion on the individual, another argument against disenfranchisement could derive from epistemic injustice – i.e., injustice related to knowledge. Again, recall our case example: As your father has a severe speech impediment and it takes more effort and time to express and articulate his thoughts and opinions, others may be too quick to dismiss his decision-making capacity or discredit his judgment. This form of epistemic injustice is triggered by preconceived opinions in which it is assumed that one lacks the ability or capacity to provide or understand relevant information (Kidd & Carel, 2016). From this perspective, the fault lies not with the speaker, but with the hearer who does not take your father seriously by basing it upon underlying stereotypes and prejudices. In her paper, Fricker (2007) brings forward another kind of epistemic justice, namely the concept of hermeneutical injustice, which centers around the ways in which non-disabled persons – the majority of society - do not have the ability to understand the experiences of those that are disabled. In other words, only your father can make sense of his own experiences. Therefore, those with cognitive disabilities should participate in political processes to ensure that the experiences of the disabled group are included and respected.

WHOSE VOICE ARE WE HEARING?

In light of the above, inclusivity is an intrinsic component of equality and this, in turn, is grounded in core democratic values in which each should be included and treated with respect (Gilligan, 2016). Instead of alienating this particular social group, full participation in democratic processes should be safeguarded to promote integration into the community and ensure representation and inclusion. When applied to our case example: On a micro level, citizen engagement may result in tangible improvement in your father's personal life – developing his skills and knowledge as well as bridging the gap between him and others. On a macro level, your father's vote and experiential knowledge can help in building a more inclusive and fair society. Enfranchisement is a means to that end. This can be further justified by the value of personal autonomy in which one should not be limited in their

ability to exercise self-determination. Through the act of voting, one is able to vocalize and act upon one's freedoms and capabilities to improve wellbeing and each should have an equal voice. Therefore, I argue that those with limited capacity to make decisions should be allowed to vote.

However, as we have established earlier, your father has an increased need for voting assistance. Therefore, while I contend that the position of capacity-based disenfranchisement is ethically unjustified, there may nonetheless be a question as to whether it opens up new insights. That is, it highlights the unequivocal fact that those who have impaired decision-making capacity are unable to participate in political processes without the physical or cognitive support of others. Because of this dependency, they are more susceptible to undue influence. Then, we could question the following: To what extent are the care recipient's interests adequately represented in the political process? While this does not justify political exclusion, what does warrant our attention is the true meaning which lies behind the vote. That is, whose voice is actually doing the speaking?

CONCLUSION

In this chapter, I have argued that despite the need for assistance, those with diminished cognitive capacity should not be excluded from political decisions. I began chapter two by examining whether this particular social group should be disenfranchised on the basis of fair elections. I contested this view by claiming that capacity-based disenfranchisement harms personal and societal well-being. Furthermore, political inclusion safeguards respect for autonomy. Viewed from the respect-based account of dignity, one should be treated and recognized as equals. Therefore, we can conclude that your father should indeed be included in political practices to ensure both individual and social justice. In the following chapter, I will argue that assisted voting is the means to achieve this end. However, as we have established, some degree of intervention is necessary to vote. That is, those with diminished capacity cannot cast a ballot without the assistance of others. The following section will further discuss who is best suited to guide the support voting process to ensure an adequately represented vote.

CHAPTER THREE: *ASSISTED VOTING*

The above chapter has argued that no one should be prevented from voting based on capacity related grounds – i.e., impaired decision-making capacity should not rule out voting. In Western ethics, autonomy is a core moral and political value which promotes self-governance in which each individual may decide freely according to their own authentic desires and values. Thus, the individual should be allowed to freely decide how to live one's life without coercion, interference, or limitations. However, herein lies the discrepancy. Those with diminished capacity may not be able to make certain decisions entirely on their own. In other words, supported voting is a two-person job. While I have argued that the care recipient should be allowed to vote, the supported voter has to put in time and effort to make this a reality. This chapter will discuss who is best equipped to support the decision-making process of voting. In the majority of informal caregiving cases, a family member is selected to be the supported decision maker (Pego & Nunes, 2018). However, to what extent is this culturally appointed role fair when approached from the family caregiver's vantage point? In the first section, I will propose that the allocation of responsibility and duties are overly demanding. In the second section, I will claim that, while it may be burdensome, family members are the most-qualified candidates to guide the process of supported voting to reach a fair and informed decision because of physical and relational proximity. In the following section, I will further justify supported voting by relatives on the grounds of family autonomy, narrative, and belonging. Moreover, as I have stated earlier, a degree of human intervention is required for individuals with ABI to be active citizens. By retaining the decision-making process within the family, outside coercion and external interference can be minimized. Notwithstanding, the element of intrusion is not entirely averted. Therefore, the last section will embark upon the degree to which involvement by the family caregiver is justified.

DEMANDINGNESS

Across human societies, the informal caregiving role is typically shared by family members as familial relations and history exerts a strong influence on the decision and choices of caring (Mazzotta et al., 2019). However, to what extent is this assigned role morally appropriate? While the previous chapter has focused on the care recipient as a victim of

injustice, this section will focus on how the task of supported voting affect the appointed caregiver and how the act of caregiving – and thus the associated task of supporting in the decision-making process of voting - could be perceived as overly demanding. To illustrate, let us return to our case example. Due to the suddenness and severity of the stroke, we can presuppose that your father underwent life-altering loss of capabilities. While perhaps not easily detected when snowed under the extensive list of caregiving duties, you yourself may find yourself losing capabilities. For instance, one could argue that the allocation of responsibility and duties is overly demanding. In other words, taking on this role ultimately demands certain obligations which for you may be difficult to uphold because the act of caregiving and supporting in the decision-making process takes up a lot of time and energy. In turn, this lack of time and flexibility directly influences your own personal life.

As I have argued elsewhere, damage in the language centers of the brain can affect one's ability to communicate, write, and understand language (Zulkifly et al., 2016). This, in turn, complicates the supported voting process. Repetitive speech and language therapy for both caregivers and stroke survivors has proven to be an effective tool to enhance and maintain communication levels (Lima et al., 2021). During which, a caregiver learns how to stay organized, control conflicting emotions, and have patience to achieve effective and constructive communication. Other added responsibilities might entail keeping topics simple, allowing the stroke survivor to process and grasp the information, patiently awaiting their responses, and resisting the temptation to answer on one's behalf. While speech therapy has shown to be effective means for the care recipient to regain a degree of independence, for the caregiver it could be considered a laborious task. In other words, to adequately help with assisted voting, the preparation needed and the process of assisted voting itself are often costly and time-consuming.

According to American philosopher Elizabeth Anderson – specialized in political philosophy, ethics, and feminist philosophy - many caregivers “face special problems under equality of fortune” because of the demanding duties of caregiving (1999, p.297). One may have to end or limit their employment to take care of the care recipient's needs. To illustrate, envision the following: While you used to work fulltime, you are now forced to find a parttime and more effortless job in order to combine paid work with your unpaid duties as a caregiver. Moreover, due to the lack of time and flexibility, it is impossible for you to earn the same wage as well as maintain your social life on the same level as before

you took on the caregiving role. Thus, while you contribute to a social purpose, the combination of those factors could presumably result in structural inequality in which you will face socioeconomic disadvantages.

Furthermore, supported voting could be perceived as overly demanding because it requires the family caregiver to put aside their own needs and preferences. As shown in the case example, your father is unable to participate in societal and political matters as he may not understand the risks and benefits of his vote and can therefore not apply this information without your help and support. Therefore, you, as the primary caregiver, will have to constantly initiate conversations on societal issues and frequently and patiently revisit them for your father to become aware of his desires and interests. In doing so, your own values may conflict with your father's post-stroke values. As stated earlier, your father was an avid human rights advocate, his current apathetic attitude towards current detrimental societal events has left no trace of his former convictions. Consider, for example, that his position on the political spectrum has changed. While his pre-stroke political views were more similar to yours, his current opinions no longer align with your ideas on how society should be organized. This political misalignment and conflicting interests could cause friction in your relationship (Warner et al., 2020).

To summarize, the role of informal caregiving is most commonly taking on by a family member. This section has shown that the allocation of responsibility and duties to informal family caregivers may be regarded as overly demanding because it requires putting aside their own needs and preferences and risking their own socioeconomic status. In short, while the practice of supported voting provides the means to improve the care recipient's quality of life, taking on the task can have the opposite effect on the family caregiver. It is therefore fair to consider the following: Do the benefits truly outweigh the costs?

PROXIMITY AND MOTIVATION

The previous section has stated that the caregiving duty and the associated task of supported decision-making could result in social and financial burdens for the family caregiver. How, then, can we justify the selection of family members as supported decision-makers on the practice of voting? Perhaps Donaldson and Kymlicka's (2011) view on relational-family bonds could provide us with a plausible solution. In their paper, they claim

that our social relations differ greatly depending on proximity. The ways in which proximity can be interpreted is twofold: It can either be a measure of - which I will call - physical proximity or relational proximity. Generally speaking, close relatives may best know the values of the patient as well as which decision is in the best interest and what outcome would most likely promote one's well-being, due to both physical and relational proximity. If we were to apply this to our case: You may know best what your father's political preferences and needs are because of the long-term relationship and interwovenness of your lives in which you have gained intimate and personal knowledge. Therefore, having this knowledge makes you more suitable for the task of assisted voting in comparison to other individuals who stray further in relational proximity.

However, it is important to point out that such conditions may not always be present. Indeed, one could counter this by claiming that relational family-bonds are not what matters, but rather the time spent with someone. Again, recall our case example and envision the following: What if you have not seen your father in years, but he does meet with his friend on a daily basis? Viewed from this perspective, we could indeed argue that his friend may know him better than you do. It is therefore important to note that exceptions may apply to each individual case in which a nonrelative may have better knowledge to reach a values-based political decision. Nevertheless, spending time with a person does not necessarily equate to obtaining intimate knowledge. Furthermore, what about the wants and desires of care recipients? To explain further, a study on patient preferences for surrogate decision-making during periods of decisional incapacity has found that most individuals prefer to appoint family members to act as their surrogate decision-makers. From the care recipients' viewpoint, the primary reason for preferring close family members was the belief that they know their wants, needs, and preferences best concerning how they want decisions to be made (Kelly et al., 2012).

On this view, we can assume that informal family caregiving should be cultivated and encouraged for your father's sake. However, how could this benefit you? To answer this, we should first answer the preliminary question as to why caregivers are inclined to care at all. While it is difficult to ascertain the true motivation as to why caregivers are willing to take on the caring role, a lot has been written on why a caregiver could be motivated to provide care. As I have argued in the previous section, motivation can be induced by societal norms and pressure. On this view, providing family support is a moral obligation rather than merely

a voluntary act. Conversely, however, taking on the caring role can also be influenced by one's own self-determination and intrinsic motivation (Ryan & Deci, 2000), or motivation based on self-interest (Greenberg, 1990; Lind & Tyler, 1988) or driven by empathetic emotion (Batson, 2014). One could also take on the caring role to decrease the feeling of indebtedness (Gergen et al., 1980). To elaborate further, according to Doty, family members are often more concerned for the well-being of the care recipient in comparison to those who do not have familial relations because they have "a sense of family responsibility, affection for the individual, and a desire to reciprocate past help given by the impaired elderly person" (1986, p.68). The latter derives motivational properties from the social norm of reciprocity. The conception of reciprocity creates social obligations among family members – i.e., feeling obliged to return the favor. This, in turn, serves as motivation to ensure that the decision is in the best interest of the care recipient because it will ultimately reduce their own feeling of indebtedness.

FAMILY AUTONOMY

Another way to approach how family membership matters to the justification of the duty of supported decision-making is by examining the role of the family within society. To elaborate, one could assert that we do not only live as individuals within a larger society, but we also belong to smaller social units or entities one of which the family social group is the most predominant. And just as living in a cultured society brings about responsibilities, the social contract of the family group has its own set of rules and social positions which governs and ensures peaceful coexistence.

Following this line of reasoning, I will argue that another mutual beneficial outcome of appointing family members as supported decision-makers is that it safeguards family autonomy – i.e., it prevents outside control or interference into the domestic sphere (Gilbar, 2011). Closely related to the concept of control are the two juxtaposing concepts of dependency and independency. When viewed from the individualistic interpretation of autonomy, the conception of dependency is often envisioned as the inability to have control over one's own life or being nonautonomous. Whereas, with independence, we visualize one having the capacity to choose and control one's own decisions and actions. While the discrepancy is significant, the concepts are analogous in the ways in which control plays a

central role. As we have established earlier, your father's individual autonomy is limited, and he lacks self-determination to vote for a specific party. Therefore, your father as an individual within society is dependent upon others in which he is unable to have full control over his own life. However, when viewed from family autonomy, the autonomy belongs to the family unit as one entity – i.e., all family members combined. It is from the latter perspective in which the family unit is independent from external control or interference and, instead, have a positive capacity to exercise collective control over various decisions. In short, when approached from the notions of family autonomy, independence and self-determination is safeguarded as you and your father are part of the same family entity.

In his work on surrogate authority of family members, bioethicist Dan Brock observes that the family entity is a moral unit and “for the family to fulfill powerful human needs for intimacy and privacy, it requires significant freedom from external observation, oversight, and control” (1996, p.613). Outside intrusion could invoke distrust and infringe upon family privacy, therefore, undermining family autonomy. By giving surrogate authority to family members, the care recipient can remain within familiar and safe boundaries which may facilitate self-competence and self-confidence. Moreover, family privacy is contained within familial territory, the family caregiver's privacy included. In this vein, we could argue that by keeping the decision-making process within the family unit translates directly into the well-being of the family.

Moreover, Brock continues that “the family plays a central role in forming and maintaining the identity of individual members” (1996, p.614). Our sense of belonging and identity is shaped and created according to our place in the family structure. In addition, the family creates its own language to communicate which results in a shared familial narrative. On this view, the collaborative process of supported decision-making could reinforce a strong family narrative. As portrayed in the case example, you and your father have also created your own language. One could argue that due to your familial relationship and history, it is easier for your father to express or convey information without verbally communicating and, similarly, for you to understand him without spoken words. That is, you both are speaking the same language. From this perspective, assigning the task of supported decision-making to a family member is justified as you are the most suitable candidate to understand his way of communicating and intimate knowledge remains within familial boundaries.

THE SPECTRUM OF INDEPENDENCE

Now, let us return to the central question of this chapter: Should the process of supported voting be guided by family members? Up to this point, I have argued that close relatives should take on the role of supported decision-makers on familial grounds. However, while this may deter external intervention, the possibility of intrusive involvement is not eliminated entirely. Needless to say, a shift in power dynamics occurs due to the project dependency of voting which could induce the risk of undue familial pressure or influence (Menon et al., 2020). Notwithstanding, to reach a consensus of shared decision-making in which the informal family caregiver and the ABI-relative considers options together and to achieve informed will and preferences, involvement is required to achieve an informed decision. Therefore, I will argue that moderate intervention is justified. However, this brings us to the following question: Where does one set the threshold of moderate intervention?

Danger lurks in the ways in which one may be too quick to dismiss the decision-making capacity of the care recipient or be easily enticed to overstep ethical boundaries. What, then, are the ethical limits? In other words, how to balance the scale between creating freedoms and imposing values onto the care recipient? The spectrum of independence may provide a plausible basis for assessing the extent to which family caregivers are morally permitted to substitute the care recipient in taking responsibility for voting rights. To make it more concrete, envision the following: On the spectrum of independence, we have two ends: On the one invasive side, the individual has complete autonomy, on the opposite end lies coercive paternalism in which choices are simply banned and full intervention is justified. Then, how can we apply this to our case example? As we have established earlier, your father does not tick the complete autonomous box as he needs your support in decision-making as well as your aid to vote and participate in political processes. However, a case for coercive paternalism can also not be made as he is not fully deprived of decision-making capacity and his autonomy should be respected. If not on opposite ends, where then can we place our case example?

Perhaps libertarian paternalism may provide us with a plausible solution (Thaler & Sunstein, 2003). The libertarian paternalist approach can be placed in between the two extremes and states that it is justified to affect behavior towards positive outcomes; however, one should still be allowed to choose from varying options – i.e., no interference

with the freedom of choice. Put simply, it advocates nudging in which it is morally appropriate to steer one's preferences away from bad choices and bring good choices to the forefront. Because family caregivers may know best how to improve the care recipient's wellbeing, I will argue that this comparatively benign form of manipulation is justified to ensure better choices and fair outcomes. In that vein, the libertarian paternalist approach could be a morally appropriate standard for informal family caregivers and care recipients to reach an informed and shared decision on voting. Now that we have determined the degree to which involvement is ethically justified, we can examine which values to include in the decision to vote.

CONCLUSION

This chapter focused on the justification of the commonly assigned role of informal caregiving to family members. I began this chapter by proposing that the allocation of responsibilities and duties which accompany supported decision-making may be perceived as burdensome as it could negatively impact one's socioeconomic status and well-being. In the following section, I focused on the mutual benefits of informal caregiving done by family members. Here, I argued that the benefits outweigh the burdens because it satisfies the caregiver's motivational needs. Approached from the perspective of care recipients, I have argued that their preferences and needs may be best understood by someone who is close in relational and physical proximity. In the following section, I further justified the selection of family members as supported decision-makers on the practice of voting on grounds of family autonomy. That is, intimate knowledge is safekept within familial boundaries. The last section has stated that while outside intervention is deterred, it is still possible for the caregiver to intrusively intervene. Therefore, I claimed it is ethically impermissible for the caregiver to go beyond the realm of libertarian paternalism - i.e., affecting behavior is allowed if it does not interfere with the freedom of choice. To recap, while this chapter has illustrated that family members are the most-qualified candidates to guide the process of supported voting to reach a fair and informed decision, I argue that only a moderate intervention in the supported voting process is allowed. In other words, caregivers should leave room for the care recipient's values, beliefs and preferences, however, they are permitted to steer one's preferences away from bad choices and bring good choices to the

forefront. Now that we have determined the degree to which intervention is ethically justified, the following chapter will examine which values, if any, should be included in the decision-making process of voting.

CHAPTER FOUR: *PRIORITIZING VALUES*

Now, let us briefly recap the previous chapters. In chapter one, I laid down the groundwork of the process of decision-making within the healthcare context. Chapter two discussed if those who lack decisional capacity should be allowed to vote. Here, I have argued that those with cognitive disabilities should not be excluded from political participation. However, to achieve this, support in decision-making and assisting in voting is a necessity. Chapter three scrutinized the extent to which a family caregiver is adequately equipped to guide the decision-making process of supported voting. Due to relational proximity and motivation, the informal family caregiver may be best suited to help with decision-making process of voting. In this chapter, I will claim that the supported decision-maker has an ethical responsibility to include and act upon various values and principles. I will zoom in on how the supported decision-maker should fulfill their role and what exactly the voting decision should be based on. The following sections will examine which values to prioritize and center around the following question: How should the informal family caregiver assess which values to incorporate to reach a shared informed decision on voting? The first section will differentiate between two value-categories: *pre-values* and *post-values*. In the second section, I will discuss how *pre-values* should be incorporated to respect precedent autonomy. In the third section, I will argue that, rather than solely focusing on precedent autonomy, *post-values* should be included to respect dignity and the current and post-stroke-self. Here, I will build upon the work of Nancy Jecker in which she argues against the privileging of midlife values – i.e., prioritizing and applying the concept of autonomy to all stages in life. Instead, each life stage requires different ethical analysis. The fourth section will further examine the notion of the authentic self and the ways in which the family caregiver should avoid their own bias towards favoring a particular version of the self. Lastly, the concluding section will provide a summary of the chapter and discuss how the family caregiver should approach the supported decision-making process in situations of political indecisiveness.

VALUE-CATEGORIES

It is blatantly obvious that complexities arise in stroke cases. A previous study conducted by the Stroke Association has shown that 77% of victims suffer from memory loss (Tang et al.,

2020). Most commonly, there are two types of memory which can be affected by strokes; verbal or visual memory (Lugtmeijer et al., 2021). The former is an instant loss of memory having to do with language – such as forgetting names of loved ones, stories, and events. The latter is a loss of perceptual processing of, for instance, faces and the inability to recall images, situations or objects of what has been previously seen. Related to this, however, is that it is not merely verbal and visual memory what is lost, it is the experience, thoughts and values one has collected over the years. Put simply, it is a reset back to older values which may even be unbeknownst to the caregiver. As our case example has shown, your father, post-stroke, has a mix of old and new values entangled within this new persona. Then, we could ask the following: Which values should be prioritized when elections are coming up? The following sections will differentiate between two value-categories of which I have termed: (i) *pre-values* or the expressed preferences or will of the pre-stroke version of oneself – i.e., before having suffered ABI; and (ii) *post-values* which entails the expressed will or preferences in the now or after having suffered ABI. The next sections will scrutinize the following questions: Should the *pre-values* trump *post-values*, vice versa, or should we assign equal weight?

PRE-VALUES: RESPECTING PRECEDENT AUTONOMY

Again, let us revisit our case example. As the elections are coming up, you two have a decision to make. For most of his adult life, your father has rarely moved from the left of center on the political spectrum. However, after having discussed many propositions and stances on a broad array of political issues, it seems that now other political parties may best represent his views in an election. In short, substantive differences in political preferences can be found prior and after his stroke. From your perspective, it may feel counterintuitive for him to vote on a political party he would before his stroke never would have considered – even if this is his uttered opinion now. Furthermore, even after having intensively revisited the political content, it might be possible that you still question which values should be prioritized to reach an informed definitive decision. Then, how to approach this?

As I have stated earlier, Dworkin argues in favor of respecting one's precedent autonomy (1986, p.10). In chapter two, I have argued that disenfranchisement of those with

impaired cognitive capacity is ethically impermissible because one's precedent autonomy should be respected. In his later work, Dworkin goes even further by stating that a "person's right to autonomy requires that his past decisions about how he is to be treated if he becomes demented be respected even if they contradict the desires he has at that later point" (1994, p. 228). When translated to our case, your father's current political preferences and interests – i.e., *post-values* - may be considered redundant or negligible, according to Dworkin. Put differently, his precedent autonomy surmounts his current preferences and interests. Instead, his expressed will and preferences he had forged prior to his stroke are only what matters.

If we were to follow Dworkin's reasoning, this would mean that you as your father's caregiver are justified to approach supported voting purely from *pre-values* in which you are allowed to completely disregard his current political stance and base the political vote solely on your own value judgment. However, herein lies a discrepancy. That is, neglecting your father's *post-values* directly contradicts all previous arguments I have brought forward in chapter two in which I discredited capacity-based disenfranchisement. There, I have stated that those with diminished cognitive capacity should not be excluded from political decisions because their autonomy should be safeguarded and one should be treated and recognized as equals.

At the same time, however, it could be argued that by entirely dismissing his precedent autonomy, one fails to acknowledge the significance of the person he was prior to the stroke. For a long time, he embodied specific political preferences and values. It made him the person he was prior to his affliction. I, however, argue that by incorporating *post-values*, it does not necessarily exclude his *pre-values* or precedent autonomy as these could derive from the caregiver's influence. Recall that in chapter three, I stated that the supported voting process cannot be adequately guided without the caregiver's value-judgment, therefore, the caregiver is allowed to moderately intervene in the process. On this view, the caregiver is allowed to guide the supported voting process based on *pre-values* or precedent autonomy – i.e., within libertarian paternalistic limits. If, for example, you may know what is in the best interests for your father, you are allowed to steer his current preferences away from bad choices and bring good choices to the foreground. Put simply, in contrast to Dworkin, I argue that the current self and values of the care recipient should still have a choice to voice one's political preferences, however, his precedent

autonomy may also be safeguarded by steering *pre-values* to the forefront.

In short, while we have argued that respect for precedent autonomy rules out disenfranchisement, I claim that respect for precedent autonomy does not justify the caregiver's right to exclude his *post-values* in the supported voting process. Instead, solely basing the political decision on *pre-values* – or precedent autonomy - is morally indefensible. That is, in merely respecting his precedent autonomy, you fail to respect your father's present autonomy. Furthermore, you fail to respect his dignity – i.e., by favoring precedent autonomy, his current self and *post-values* are unworthy of ethical consideration.

POST-VALUES: RESPECTING DIGNITY

The previous section has argued that your father's *post-values* should be included. However, the caregiver is allowed to steer his political views towards his *pre-values*. I claim, however, that it is not morally permissible to solely focus on his precedent autonomy because this would neglect his current self. Typically, within Western societies, autonomy is inextricably linked to the concept of selfhood. These societies support individualism and lay emphasis on the value of autonomy (Henrich et al., 2010). In short, a person is, first and foremost, an autonomous individual with needs, wants, and preferences and should be free to pursue one's own goals. In this section, however, I will argue that we should shift our focus to respecting your father's dignity and current self. In other words, by respecting his *post-values*, you respect his dignity and current self.

In her book *Ending Midlife Bias*, Nancy S. Jecker, an American philosopher and Professor of Bioethics & Humanities at the University of Washington School of Medicine, introduces a new philosophical framework which focuses on different values at different stages of one's life which she defines as the "life stage relativity of values" (2020, p.6). To explain further, our values shift across our lifespans. Broadly speaking, we can differentiate between three major life stages or periods – i.e., early, mid, and later life. From infancy to young adulthood, one is vulnerable and needs constant nurturing. Therefore, values of caring and trust are most important. Whilst growing from young into adulthood, the predominant value of midlife primarily centers around valuing autonomy. That is, as we mature, our independence grows along with it. In later life, however, our mental and physical state gradually deteriorates. In this stage, we fight to retain our capabilities,

functioning, and keep our dignity intact. Jecker further claims that, as we grow older, “we become more focused on maintaining human dignity because we are more at risk of losing basic human capabilities” (2020, p.26). According to Jecker, however, the ethical incongruity lies in the ways in which midlife values are placed above all others in which autonomy is the central value. Despite which life stage one is in. In other words, Western societies tend to centralize autonomy and apply these midlife values to all other life stages. This is what Jecker calls *midlife bias* and refers to the privileging of midlife values over other life stages. This bias, however, leads to “a focus on respect for autonomy and associated values of noninterference and self-determination, often to the exclusion of other values, such as caring, trust, and dignity” (2020, p.8). Instead, she suggests that we should draw on wider values. In other words, “the conditions of our lives make different values right for us at different life stages” (2020, p.21).

Then, what values should we regard as central to your father? Because of the stroke, his capacities have increasingly changed. While autonomy and self-determination may have taken center stage prior to his stroke, the previous chapters have shown that these are no longer focal after having suffered brain damage. In an instance, he jumped from midlife values to later life values. Therefore, it seems, that by approaching assisted voting solely from the principle of respect for autonomy is infeasible as its associated values of self-determination and noninterference cannot be met or upheld. That is, your father is unable to make and act upon choices without assistance.

In chapter two, I already briefly touched upon respecting dignity, especially the notion of recognition. In his article, Darwall (1977) differentiates between two kinds of respect: recognition and appraisal respect. The former account of recognition respect is beneficial to our case example regarding how to approach the supported decision-making process from the principle of respect. Darwall states the following: “To say that persons as such are entitled to respect is to say that they are entitled to have other persons take seriously and weigh appropriately the fact that they are persons in deliberating about what to do” (1977, p.38). He continues by saying that “others may or may not respond appropriately to the presented self. To fail to take seriously the person as the presented self in one's responses to the person is to fail to give the person recognition respect as that presented self or in that role” (p.38). In other words, individuals present different selves in different contexts and whichever self is presented, is worthy of respect. When applied to

our case, we could argue that by favoring your father's pre-stroke-self, you fail to take seriously his presented self – i.e., his post-stroke-self. Therefore, to give your father recognition respect, his presented self and *post-values* should be respected.

To recap, in this section, I have argued that personhood should not be primarily viewed from the perspective of autonomy because it fails to respect one's dignity. That is, if your father's post-stroke self is no longer seen as an autonomous individual, and therefore not included, you fail to treat his current self with dignity. According to Jecker, we should draw on wider values which are more appropriate to his current life stage – such as caring and dignity. The following sections will further expand on identifying the self and how the family caregiver should guide the supported voting process without neglecting his current self.

IDENTIFYING THE SELF

The most recurring complaint by family members of stroke survivors is the alteration of personality and character (Bucki et al., 2019). Dealing with this is challenging, can cause problems in social situations, and often takes a toll on relationships. In short, this new persona may not be a welcomed replacement of the older self.

As illustrated by our case example, you also have experienced a personality change in your father. He is no longer able to take on the parental role and his attitude and view upon the world has changed immensely. The stroke deprived him from his old self and changed him into a new persona. In other words, you can no longer deny that his pre-stroke self has (partially) ceased to exist and he has transformed into a new post-stroke person. On this view, a clear line can be drawn on the moment he had the stroke.

However, one could counter this by arguing that your view is merely subjective. That is, it is viewed from the perspective of you, the filial caregiver in which you assume that the authentic version of your father has ceased to exist. However, can we say the same when viewed from your father's perspective? Perhaps he may not feel all that different. While he may be aware of memory loss, his current self still has memories of his old life. Unlike you, he may not perceive his pre- and post-stroke self as two entirely different people. Then, to what extent can we argue that your father has indeed changed into another person? Instead, one might claim that you are simply holding onto hope of your father going back to

normalcy - i.e., the autonomous person who he was pre-injury. This is analogous to the previously mentioned bias by Jecker. Just like the predominant value of midlife centers around valuing autonomy, what you mourn is the loss of your father's predominant pre-stroke-self which, in your view, is his true self. In our case, however, it may be possible that your father lives on for another few decades. Perhaps even as long as you knew him before his injury. Then, one could question the following: At what point, if at all, will his post-stroke-self surpass the supposed superior pre-stroke-self?

This close examination of the self is important because it directly links to how the family caregiver may guide the assisted voting process. That is, which values, or preferences should be prioritized? As stated earlier, close relatives may know the values or what would be in one's best interest. At the same time, however, interpreting values is a slippery slope because family members often grasp onto what they knew the person to be, pre-stroke, and therefore denying the existence of a new persona (Hughes & Cummings, 2020). Then, we could question the following: Is the caregiver able to recognize and avoid their own subjectivity? On this view, I argue that, to justify assisted voting, the supported decision-maker must therefore be aware of this bias to avoid acting from their own subjectivity.

CONCLUSION

This chapter has investigated how the caregiver should guide the supported voting process with regard to old and new values. Now, let us circle back to our central question of this chapter: How should the informal family caregiver assess which values to incorporate to reach a shared informed decision on voting?

Firstly, while the sole focus should not be on his precedent autonomy – or the person he once was prior to his stroke - I have argued that the family caregiver is allowed to guide the supported voting process based on *pre-values*. That is, a libertarian paternalist approach in which you are allowed to steer the political conversation into what your father may have chosen prior to his stroke. However, while it is justified to affect his opinion towards *pre-values*, you should also allow space for him to opine his *post-values*. Put simply, to reach an informed political decision, your father should thus be allowed to choose from a range of choices based on both *pre-* and *post-values*.

Secondly, I have argued that, as a caregiver, you should be aware that your father may not experience his personality as being altered as such. His post-stroke-self deserves

recognition respect. Therefore, an ethical concern arises by merely focusing on his pre-stroke autonomous self as you fail to treat his post-stroke self of being worthy. Put differently, his post-stroke-self has the right to be valued and respected for its own sake. To justify supported voting, I argue that the caregiver should be aware of this bias and dissuade favoritism towards autonomy.

However, what if a situation of political indecisiveness occurs in which it is not possible to reach an informed and shared decision on voting? Envision, for example, that after having had many talks with your father about the upcoming election, the overload of choices is reduced to only a few options. At this point, however, your father is unable to arrive at a final political decision on who to vote for as he considers the remaining alternatives to be equally acceptable. Put simply, the final say is up to you. I will argue that only after pre- and post-stroke values are taken into ethical consideration, the caregiver is justified to base the political vote solely on their own value judgments. However, herein lies another moral criterion. That is, the ultimate political decision should be based on the best interest standard in which you build upon your own political knowledge and decide which of the remaining options would serve your father's best interest.

To explain further, let us revert to the two guides for decision making when a patient lacks decision-making capacity previously discussed in chapter one. There, I differentiated between two standards: The *substituted judgment standard* and the *best interest standard* (Chaet, 2017; Johnston, 2012). The former focuses on how to act as a substitute, while the latter guides the decision-making process from considering what would be in one's best interest. When making the final decision on who to vote for, I will argue that you should not invoke the substituted judgment of 'what would my autonomous father have chosen or decided himself?' but rather decide on what is in his best interest. The reason for this additional moral criterion is that the remaining voting options already derive from *pre-* and *post-values*. At this point, it is no longer necessary to reflect upon his values as both *pre-* and *post-values* have already been included in the supported voting process. By basing the final political decision on substituted judgement, however, you are yet again failing to recognize and respect his post-stroke-self. Therefore, to conclude, the final political decision should be based on what is in your father's best interests.

CONCLUSION

Through the act of voting, one is able to vocalize and act upon one's freedoms and capabilities to improve personal and societal wellbeing. To make it possible for each individual to have an equal voice, resources should be allocated towards improving voting access and breaking down voting barriers for those who may encounter hurdles to reach the polling station. However, for individuals with cognitive impairments, additional support is necessary to cast their ballot. That is, before the actual act of voting, a deliberative process must take place beforehand to understand the voting process and to reach an informed decision on what to cast their vote.

Now, let us return to the central thesis and research question. The aim of this thesis was to answer the following: (i) Should assisted voting for people with acquired brain injury be allowed?; (ii) If so, who is best equipped to assist in the voting process?; and (iii) which of their values, if any, should be included in the decision-making process?

In chapter one, I broke ground by introducing bioethical accounts of decision-making. More specifically, distinguishing between surrogate and supported decision-making in cases of impaired cognitive capacity and how the informal family caregiver plays a role in the decision-making process.

After having laid down the theoretical groundwork, I began the discussion of the first research question in chapter two. That is, should assisted voting for people with acquired brain injury be allowed? In response to this, I have argued that, despite the need for supported voting, those with acquired brain injuries should be allowed full voting rights. Capacity-based disenfranchisement is morally impermissible because one should be treated and recognized as an equal. Moreover, inclusion of this particular group ensures representation. Instead, political participation should be safeguarded to promote integration into the community and this, in turn, helps to reinforce one's sense of belonging and to shape the ongoing construction of self-identity. Supported voting is a means to that end. However, this brings us to the follow-up question: Who is best equipped to assist in the voting process?

In chapter three, I stated that supported voting is only one task of a wide variety of caring duties and responsibilities that fall under the umbrella of caregiving. The informal caregiving role is most commonly appointed to a family member. While I suggested that the

duties and responsibilities could be considered overly demanding for the family caregiver, I have concluded that they are nonetheless best suited to guide the supported voting process because the preferences and needs of those with impaired capacity may be best understood by someone who is close in relational and physical proximity. Moreover, by keeping it within familial boundaries, intimate knowledge is protected from outside intrusion. In guiding the supported voting process, I have stated that the caregiver is allowed to moderately intervene and steer one's preferences away from bad choices and bring good choices to the forefront. This brings us to the last question of this thesis: Which of the stroke survivor's values, if any, should be included in the decision-making process?

In the fourth chapter, I differentiated between *pre-values* and *post-values* in which the former encompasses pre-stroke expressed preferences and values and the latter revolves around post-stroke preferences and values. There, I stated that, within Western societies, the emphasis mainly lies on respect for autonomy. However, for ABI-individuals it is oftentimes difficult to make decisions entirely on their own without involvement or support of others. Therefore, I have argued that we should shift the sole focus of autonomy to respect for dignity. From a caregiver's vantagepoint, it is important to recognize and respect the new persona which may emerge after a stroke. Herein lies another task for the family caregiver, that is, to recognize their own subjectivity towards favoring one's previous or pre-stroke self. The current self and values should be included and respected and therefore the caregiver should not guide the supported voting process based solely on *pre-values*. In other words, while I have argued that the caregiver is allowed to steer certain choices based on *pre-values*, one's *post-values* should not be neglected because otherwise you fail to respect one's post-stroke-self. If the political choices are reduced to only a few, yet still inconclusive, I have argued that the family caregiver is allowed to have the final say. In this case, the final decision should be based on what is in the best interest of the care recipient to ensure impartiality and to avert a repetitive cycle of preferring *pre-values* over *post-values*.

Put differently, the process of supported voting can be roughly divided into three stages – i.e., the early, middle, and last stage – and involves the following guidelines:

1. The preliminary step is that the family caregiver should first assess their bias or preconceived opinions on how they perceive authenticity and how these are linked

to versions of the self. Before starting the supported voting process, the caregiver should be aware to be attentive and treat the current self with dignity.

2. The next step is to include the following values in the process of supported decision-making: (i) *pre-values* – which derive from the family caregiver’s knowledge of the expressed preferences or will of the pre-stroke version of the care recipient; and (ii) *post-values* – or current preferences which derive from the care recipient directly. While the caregiver is permitted to bring in preexisting values, the caregiver should leave room for the care recipient’s current values, beliefs and preferences. To navigate the broad range of choices during the process of supported decision-making, the caregiver is allowed to steer preferences away from bad choices and bring good choices to the forefront before letting the care recipient reach a final decision – i.e., within the limits of libertarian paternalism.
3. The last step is only required in cases of indecisiveness. That is, when the political choices are reduced to only a few options and, at this stage, the care recipient is unable to decide, the family caregiver is allowed to make the final value judgment based on the best interest standard.

WHERE DO WE GO FROM HERE?

On a much broader level, the main contribution of this thesis will be to provide a basis for ethical guidance for informal family caregivers in real-life moral dilemmas which accompany the joint process of supported decision-making. The main aim of this thesis was to highlight that even when those with acquired brain injuries are affected in their ability to communicate, write, and understand language, others should not fall into the treacherous pitfall of treating the post-stroke-self as having lower moral status. While communication may be disrupted and thus making it more difficult to interact and make sense of what is going on in the heads of those with acquired brain injury, their capabilities should not be infringed upon, and their sense of being should be respected. While this thesis has focused primarily on supporting the care recipient with the process of voting, the same criteria and beforementioned steps could be expanded to other supported practices; however, different moral criteria may apply. Therefore, further research is needed to determine the ethical consideration of each supported practice.

In addition to this, certain limitations of this research should be pointed out. Firstly, it should be noted that other ethical concerns may arise which were beyond the scope of this paper. For example, who should be held accountable when final decisions result in negative consequences? Besides this, the conclusions of this thesis are based on the relational account of supported decision-making in which one cares for a family member with acquired brain injury. However, while family members are most commonly appointed, informal caregivers could also entail individuals who are unrelated to the care recipient. Viewed from this, for instance, other motivational properties may apply. Likewise, this thesis is based on individuals with cognitive impairments caused by acquired brain injury. However, different moral criteria may apply to individuals with other neurological disorders. These limitations should be taken into consideration in any forthcoming study. Furthermore, more research should be done to better understand the influence and ethical behavior of the informal caregiver with regard to the process of supported decision-making of those with impaired decisional capacity.

Going back to the beginning of this thesis, societal ageing results in higher care demands, which, in turn, leads to the allocation of responsibilities and duties to informal caregivers. While a vast amount of literature has been written on how the loss of decisional capacity may impact the self, identity and personhood of individuals who suffered severe brain injuries, less has been devoted to the role of the caregiver and the newly assigned role of supported decision-maker. Amidst adjusting to the new normal, the allocation of responsibility of decision-making is often overlooked, however, it can have severe consequences for both the carer and care recipient. I have argued that the informal caregiving role serves as a social purpose and should be considered morally praiseworthy, however, we should not forget how carrying its moral weight may impede the caregiver's wellbeing. To conclude, caring for ageing populations entails caring for informal caregivers because those who provide informal care are a meaningful resource to their care recipients and a crucial component of long-term healthcare systems. Therefore, further research is needed to help understand and recognize the often-hidden ethical responsibilities and burdens of the caring role to establish a fair and mutually beneficial equilibrium of caregiving.

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