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# "If I lose my mind, she will take care of me." The importance of relational autonomy and legal planning in later life

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Personal autonomy is among the core values of modern Western liberalism, but what is the precise meaning of this term, and why is autonomy valued so highly? What if one is no longer fully capable of self-determination, as may be the case as we grow old? In this article, we clarify the meaning of personal autonomy, claim that its importance is connected to its contribution to human well-being, and introduce some legal instruments with which to support the autonomy of older people. We illustrate our theoretical and legal analysis by drawing on the actual experiences of older people in Finland. Our empirical material supports the theoretical claims about autonomy's importance, its connection to well-being, and its relational nature. However, this article also reveals that people should be more aware of the importance of engaging in legal planning in advance to ensure an autonomous life until the end of their lifespans.

**Keywords:** autonomy, older persons, relationality, well-being.

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#### Introduction

Personal autonomy—the freedom to govern one's life according to one's own conception of good—is highly valued in modern Western societies. In philosophy, personal autonomy is often taken to be the very feature that confers a special worth upon us and distinguishes us from non-human animals. For example, James Griffin claims that "we value our status as human beings especially highly . . . This status centres on our being agents—deliberating, assessing, choosing, and acting to make what we see as a good life for ourselves." (Griffin 2008, 32) The importance of autonomy is also enshrined in many human rights documents, most notably in the UN Convention on the Rights of Persons with Disabilities, the guiding principle of which is "[r]espect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons." (CRPD 2016, article 3, section 1)

But what does personal autonomy mean, and why is it so important to us? And how can the law help us realize it even when our decision-making capacities are not fully functioning, as may be the case when we grow old and frail? In our article, we clarify the concept of personal autonomy by drawing on the ongoing active philosophical research surrounding it<sup>5</sup> and introduce the ideas of procedural, individualistic, and relational autonomy. All of these conceptions capture important dimensions of autonomy, but especially the relational aspect is pertinent to our discussion of older persons' autonomy, which, as we will show, is often realized within a network of relationships. We also explain the importance of personal autonomy by showing how it is connected to human well-being (e.g., through bringing mental contentment and meaningfulness to one's life). Furthermore, we introduce certain Finnish legal instruments intended to support the autonomy of people whose decision-making capacities may be diminished.

We link the article to the Finnish legal context, as we draw, in our article, also on the actual experiences of older people in Finland. By analyzing interviews with 16 persons who were born in the 1920's and 30's, we show what autonomy concretely means to them, how it is essential to their well-being and meaningfulness in life, and how it is realized within relationships and autonomy-supporting legal instruments. In other words, we aim to connect the theoretical and legal analysis about autonomy to the lived realities of older persons. Although our empirical data is not very big and doesn't warrant making sweeping generalizations, some tentative conclusions can be drawn from it, and above all, the material raises interesting questions for future research. For example, since both philosophical reflection and our interviews point towards the importance of relations for the realization of autonomy, this suggests a need for law to better recognize this, and to move away from an overly individualistic picture of human beings. Our study also indicates that there is a danger of

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<sup>&</sup>lt;sup>5</sup> See, for example, Mackenzie and Stoljar 2000; Friedman 2003; Taylor 2005; Christman and Anderson 2005; Jennings 2007; Christman 2009, 2020; Sheddon 2013; Buss and Westlund 2018; Stoljar 2022.

leaving the autonomy-supporting legal arrangements to the last minute before one's decision-making capacities begin to diminish. This raises the question of whether there is sufficient information and counselling available regarding the legal instruments intended to enable autonomous agency at the end of one's lifespan. All in all, the strength of our article consists in combining theoretical, legal and empirical approaches to better understand the nature and value of autonomy, and in giving voice to people from an age-group that is rarely heard in academic research.

# What autonomy is and why it matters

# Conceptions of autonomy

Before it is possible to discuss why autonomy is so important for us, it is necessary to briefly examine the concept of autonomy. Literally understood, autonomy means *self-rule*:<sup>6</sup> an autonomous person governs their own life, instead of being ruled by forces external to themself. However, apart from this minimal definition, there is not a single shared understanding of the concept of autonomy among theorists but, rather, many different accounts.<sup>7</sup> For the purposes of this article, we must clarify the procedural, individualistic, and relational conceptions of autonomy.

The idea in procedural accounts of autonomy is that in order for one's choices to really be one's *own* choices, the person must have reflected about their deepest values and concerns, and they must live their lives according to such values. An autonomous person's choices emanate from their "true self", rather than from their trivial whims and impulses, or from somebody else's wishes. As Marilyn Friedman puts it, "[s]omeone is self-determining when she acts from the sake of what matters to her, what she deeply cares about, and, in this sense, who she 'is'" (Friedman 2003, 6). Another way to put this is to say that autonomous persons are *authentic*: they have reflected about who they really are and their actions in life mirror the results of this reflection.

Such an account is "procedural" in the sense that it focuses on the internal structure of a person's psyche and the processes of critical reflection. Being autonomous means being able to critically evaluate one's beliefs, values, and preferences and endorse or reject some of them based on this evaluation; this is a way of finding out who one really is – what constitutes the "self" of a self-determining agent. Harry Frankfurt (1971) calls such critically evaluated preferences "second-order desires", in contrast to unreflective "first-order" desires. Authentic, autonomous persons can act according to their second-order desires (such as helping their sick spouse), even if it means that sometimes they

<sup>&</sup>lt;sup>6</sup> The term "autonomy" derives from the Greek words autos, which refers to "self," and nomos, which refers to "law" or "custom." Online Etymology Dictionary, entry for "Autonomy" (https://www.etymonline.com/word/autonomy).

<sup>&</sup>lt;sup>7</sup> Regarding the various conceptions of autonomy, see, for example, Mackenzie and Stoljar 2000, 3–31; Christman and Anderson 2005b, 1–23; Christman 2020 and Stoljar 2022.

must suppress their immediate first-order wants (such as going out with friends).

This of course requires a capacity "to reflect upon and endorse (or identify with) one's desires [and] values." (Christman 2020, sec. 1.2) However, as Friedman points out, this reflection does not need to be something that we do all the time, and it does not need to be overly intellectual or rational but can also be based on emotions (such as love for one's spouse), and can even be subconscious (Friedman 2003, 8–10). Thus, a procedural account of autonomy need not set a very high threshold for autonomy so that only beings capable of sophisticated meta-cognitive skills could have it. However, some kind of rudimentary ordering of one's preferences at some stage in one's life is required.

Thus, in procedural accounts, the focus is on the *internal* aspect of autonomy - on the self that has a unique stance or perspective onto the world. The *content* of the person's desires, beliefs, and values is not relevant. This is why procedural accounts are sometimes called "content-neutral" conceptions of autonomy (Mackenzie and Stoljar 2000, 13–14; Christman 2005, 277). This means that a person can be autonomous even if they choose something that others think is not wise or in the best interests of the person. One can even choose to give up one's autonomy in some matters (for example, one can choose to let God choose one's time of death, to use an example from our empirical material). This is not contrary to autonomy, as long as such renunciations of autonomy are based on one's deeply held commitments instead of being externally forced upon one.

Sometimes the focus in accounts of personal autonomy is more on the person's self-sufficiency and independence. These can be called *individualistic* conceptions of autonomy. In an idealized version of such a conception, autonomous agents are seen in isolation from their relationships to other people and the surrounding society; as atomistic, mentally and physically competent, self-sufficient individuals. Such individualistic tendencies can be found e.g., from Tom Beauchamp's and James Childress's influential definition, according to which autonomy means "self-rule that is free from both controlling interference by others and from limitations, such as inadequate understanding, that prevent meaningful choice." (Beauchamp and Childress 2001, 58)8 An atomistic, competent, and self-sufficient self is also presupposed, at least in feminist readings of, for example, Immanuel Kant's or John Rawls's philosophy (Anderson, Willett and Meyers 2021; Stoljar 2022). For example, Kantian selves have been claimed to be "abstracted from the social relations in which actual agents are embedded" (Stoljar 2022, sec. 1), which leads to the assumption that autonomous agents are self-sufficient.

It is debatable whether any philosopher has ever adopted such a fully individualistic conception of autonomy and the self; it is more an idealization of

<sup>8</sup> It has been claimed that Beauchamp and Childress provide "the most influential account" of the principle of respect for autonomy in contemporary medical ethics. Gómez-Vírseda et al. 2020, 1.

some tendencies that underly traditional Western liberal thinking. And although these tendencies can lead to undesirable consequences if given full rein (such as increased selfishness and disregard for other people), it can be acknowledged that to the idea of personal autonomy belongs a certain amount of independence and self-sufficiency, and that these are valuable aspects of life especially as one gets older (as we will see later in this article). Conceptually, personal autonomy presupposes a self that has a distinct identity from others, whose body is separate from other bodies, and who has its own unique viewpoint to the world; in this sense autonomy is necessarily an individualistic idea. And, as Friedman points out, the exercise of autonomy is a way of further individuating oneself from others – of making life look like one's own life that reflects values and concerns that are important for just this person (Friedman 2003, 16–17).

Thus, individualistic accounts of autonomy are onto something important; the distinctness of individuals from one another, and the value of living life according to one's own reflected preferences, cannot be denied. But individualistic accounts can be criticized to the extent they forget or ignore the relational and social preconditions of autonomy. This feminist (and also communitarian) critique of individualistic liberalism has been highly influential in recent decades, and relational accounts of autonomy have gained ground (see e.g., Nedelsky 1989, Mackenzie & Stoljar 2000, Llewellyn & Downie 2012). In such accounts, other people are seen as the necessary conditions for autonomy, something without which none of us could have developed into autonomous beings or exercise autonomy in our daily lives.

In relational autonomy, human selves are seen as relational. This is not merely, as Jennifer Llewellyn and Jocelyn Downie point out, "an empirical claim about the way in which human beings live." (Llewellyn and Downie 2012, 4) Of course, most of us live with or in close proximity to other people - in families, neighborhoods, or communities. The claim about relational selves is a more fundamental one: the human self "is constituted in and through relationship with others." (Llewellyn and Downie 2012, 4) This means, for example, that we are born into a social context and are someone's sons or daughters or brothers or sisters, that we are citizens of certain states and speakers of languages that existed before us, and that we are dependent on other people's care in order to survive in childhood and our personality appears in how we relate to other people and our origins (Llewellyn and Downie 2012, 5). In short, other people are not only causally necessary for our selfhood but essential to our self-understanding, to our sense of who we are (Mackenzie and Stoljar 2000, 7–8).

If we accept this view of ourselves as relational beings, it does not mean that we cannot be autonomous. However, it means that autonomy cannot be

<sup>&</sup>lt;sup>9</sup> For example, Rawls acknowledges that an individual's self-respect has a social basis: it requires a community in which one's endeavors are seen as worthwhile (Rawls 1971, 440-442); and Kant's later views on self and autonomy have been interpreted to include a necessary relation to community (Shott 1998, 96-7).

<sup>10</sup> Annette Baier captures our relational nature by saying that we are always "second persons." Baier 1985, 84-85.

understood as total independence from others. Instead, autonomy must be seen as "a capacity made possible by constructive relationships." (Nedelsky 2020, 30) In other words, the capacities needed for autonomous agency develop only with the help of other people's support and within suitable social structures. Joel Anderson and Axel Honneth (2005) have argued that autonomy presupposes, for example, that a person has enough self-trust (i.e., that the person trusts and values their own feelings, desires and opinions), self-respect (i.e., that the person regards him- or herself as equal to others and as someone who is treated as a rational agent), and *self-esteem* (i.e., that one sees one's projects and endeavors as worthwhile and meaningful). Anderson and Honneth emphasize that for these self-directed attitudes to develop, relations of recognition are required. For example, the development of self-trust requires loving care in early childhood, so that a child learns to see its basic needs as worthy of being satisfied; the development of self-respect requires that a person is included in deliberation and decision-making; and self-esteem requires respectful and tolerant attitudes by others towards various ways of living (of course as long as those ways do not undermine anyone else's exercise of autonomy). Society can support the development of these capacities, e.g., by policies that promote good childcare; or suppress their development by various types of subordination, marginalization and exclusion (Anderson & Honneth 2005, 131–135; see also Kauppinen 2011, 268-269).

If autonomy's relational aspects are acknowledged, then it need not be reserved only for fully (mentally and physically) competent adults. That is, there are no conceptual barriers for, for example, older persons with dementia or disabled persons autonomy, given that suitable support is provided for its exercise. Other people can, for example, gather information and explain it to the person, help the person understand the consequences of various decisions, or assist the person with communication (Devi 2013, 795). And such support should be provided for everyone, given that the exercise of autonomy is an important ingredient of human well-being. This is what we try to show in the next section.

To sum up, we have in this section shown how some accounts of autonomy emphasize living according to one's self-reflectively chosen values, some emphasize independence and self-sufficiency, and some the relational nature of humans and the social preconditions of autonomy. These different accounts need not be seen to be mutually exclusive. Instead, they can be seen to capture different aspects of the complex concept of personal autonomy. Autonomy means following one's "real self" that is distinct from other selves, but that has been constructed with the support of other people and that one realizes with the help of other people. And of course, many other practicalities need to be in place for a full realization of personal autonomy: society must provide enough opportunities and resources so that one can genuinely choose among alternatives. Because autonomy depends on many agent-external factors, it

means that those external factors can also hinder a person's development into an autonomous agent or obstruct autonomy's exercise in practice. Thus, one's close relations as well as larger societal structures can both enable and disable autonomy. In this article, the emphasis is on the enabling side – on the legal means that support autonomy and on older people's positive experiences of relational autonomy, since these came to the fore in the interviews. However, it must be remembered that there may be societies that do not provide such legal support and that close relations can also negatively impact older persons' autonomy.

#### *The importance of autonomy*

After having clarified the concept of autonomy–or, rather, after having shown how complex and multi-faceted a concept it is–we shall turn to the question of *why* it is valued so highly. We argue that autonomy is an essential part of our *well-being*. Well-being, in turn, requires no further justification; supposedly, everyone wants their lives to go well rather than badly.

Autonomy's importance for well-being can be seen by examining the weaknesses of what Anna Alexandrova (2017, 157) calls the "three big" philosophical theories of well-being – hedonistic, desire-satisfaction, and objective list theories. *Hedonism* defines well-being as the balance between pleasurable and painful experiences; the more pleasures one's life contains, the better it goes for one (Fletcher 2016, 8–9). The famous problem in this theory is that it seems to ignore our agency: if the sole measure of well-being is the experience of pleasure, it would seem that it is irrelevant *how* the experience is produced – whether by someone secretly adding pleasure-producing drugs to our food, or by an "experience-machine" that produces pleasurable experiences by manipulating our brain<sup>11</sup>, or by our own efforts and choices. The fact that most of us value pleasure that is the result of our own efforts and strivings reveals that autonomous agency is an essential part of well-being. There is something more worthwhile in actively doing and achieving things that one enjoys, as compared to being a passive recipient of pleasure.

In the *desire-satisfaction theory* well-being is defined as having one's desires or preferences satisfied. It differs from hedonism in that one can desire other things than one's own pleasure – for example, that one's colleague will be cured of his cancer. (Fletcher 2016, 34). The problem in desire-satisfaction theories is that desires can be nonautonomous. They can be the result of, e.g., manipulative upbringing or direct brainwashing, or they can be addictive desires one does not want to have. (Lagerspetz 2011, 91) In such cases, it would seem counterintuitive to say that getting what one wants enhances one's well-being. The wants should not be the result of nonautonomous processes, and they

<sup>&</sup>lt;sup>11</sup> The famous "experience-machine" thought experiment is made in Nozick 1974, 42-43.

should be in alignment with one's 'true self' – requirements that again reveal how autonomy and well-being are connected.

The third philosophical theory of well-being, *objective list-theory*, detaches well-being conceptually from person's own subjective views; well-being is constituted by things that are objectively good for the person, whatever the person's own attitude towards those things is (Fletcher 2016, 50). The obvious worry connected with this theory (or group of theories) is that it can justify paternalistic policies: we could e.g., be forced to a certain lifestyle or occupation, on the pretense that it is for our own well-being. Once again, the lack of attention to personal autonomy – to the importance for us to decide ourselves what constitutes a good life – makes this approach to well-being seem defective.

Our aim here is not to adjudicate between these theories but just to point out that however well-being is defined, autonomy must be included in the definition: it is clearly an important component of human well-being. How exactly are autonomy and well-being connected? If autonomy is understood to include living an authentic life (i.e., if autonomy includes a procedural dimension), the connection is easy to understand. As we have seen, autonomy can be explained procedurally, as involving critical reflection about one's deepest commitments and values. A person is autonomous and authentic when they can live according to values and principles that matter to them and are not constantly detracted from them by superficial urges and desires. Such inner harmony regarding one's psyche - the feeling that one is not torn between conflicting desires, that one lives a life that one truly wants to live, and that one has not compromised one's most important values - is, without a doubt, a source of well-being and peace of mind. In contrast, if a person's principles and desires are in constant conflict or they feel alienated from their values or cannot identify with any of their desires, such a person is not doing as well as they could. If one is passively thrown about by unwanted or unendorsed desires, one cannot, according to Frankfurt, be properly called a *person* (Frankfurt 1971, 16).

In the liberal philosophy of John Stuart Mill, autonomy is closely connected to human *flourishing* and *perfection*. Mill claims, in his essay "On liberty," that

...[t]he human faculties of perception, judgment, discriminative feeling, mental activity, and even moral preference, are exercised only in making a choice. He who does anything because it is the custom, makes no choice. He gains no practice either in discerning or in desiring what is best. The mental and moral, like the muscular powers, are improved only by being used. (Mill 2003 [1859], 123–124)

Mill can be read as propounding the view that good human life consists of developing and using distinctively human cognitive and moral capacities but that those capacities cannot develop unless one learns to make individual choices (i.e., unless one learns to be autonomous, rather than blindly following

existing habits). As he puts it, "[t]he free development of individuality is one of the leading essentials of well-being." (Mill 2003, 122)

Autonomy also enhances well-being by being connected to *meaningfulness in life*. Here, we assume that an aspect of human well-being is seeing one's life as, in some sense, meaningful. Autonomy can be seen as essential to such meaningfulness. For example, according to Robert Nozick, "[a] person's shaping his life in accordance with some overall plan is his way of giving meaning to his life; only a being with the capacity to shape his life can have or strive for meaningful life." (Nozick 1974, 50)

Similarly, Joseph Raz believes that a crucial aspect of well-being is that an individual has aspirations and goals that are their *own*. They care for those goals and are committed to them and feel contentment while achieving them through their own actions. Other people may further an individual's well-being by helping that individual achieve those goals, or if they want the individual to have completely different goals, they must make the individual adopt them as his or her own goals. However, well-being is not furthered by some other person achieving one's goals on one's behalf. An essential aspect of the *meaningfulness* of those goals is lost if a person does not reach them by their own choices and actions. Thus, autonomy and well-being are connected by the meaningfulness that the exercise of autonomy brings to one's life (Raz 1986, 290-307).<sup>12</sup>

However, it should be added that, as we saw when discussing the idea of relational autonomy, it is not totally up to individuals themselves to decide what pursuits in life are worthwhile and meaningful. An important aspect of the contentment that is felt when one achieves an important goal is the reactions of *others*: their encouragement, admiration, pleasure, and perhaps even envy. Autonomy requires self-esteem, and self-esteem, in turn, is bound up with what meanings other people attach to certain pursuits, goals and ways of living. Thus, even if one's *own* agency is important for meaningfulness, at the same time, the meaningful exercise of autonomy is dependent on how other people view one's pursuits.<sup>13</sup>

Finally, the value of autonomy appears in its close connection to the concept of human *dignity*. Profound theoretical discussion of this concept is beyond the scope of this paper, and here we shall define it simply as the special worth that belongs to every human being. It is interesting that, although there are, as we saw, competing conceptions of autonomy, they all seem to agree that autonomy is essential to human dignity. This connection is made most famously in Kant's philosophy: "Hence autonomy is the ground of the dignity of human nature and of every rational nature." (Kant 1993 (1785), 41) John Stuart Mill, whose utilitarian ethics otherwise is very different from Kant's moral philosophy, agrees with Kant about the connection between autonomy and human worth:

 $<sup>^{\</sup>rm 12}\,\text{See}$  also Schnell 2009 and Martela and Steger 2016.

<sup>&</sup>lt;sup>13</sup> Antti Kauppinen, for example, describes the positively evaluative attitudes we have toward people whose lives we see as meaningful (Kauppinen 2015, 282). See also Baumeister 1991.

He who lets the world, or his own portion of it, choose his plan of life for him, has no need of any other faculty than the ape-like one of imitation...It is possible that he might be guided in some good path, and kept out of harm's way. ..But what will be his comparative worth as a human being? (Mill 2003, 124)

Harry Frankfurt also believes that the capacity for second-order desires (i.e., the capacity for autonomy in the procedural sense) is what distinguishes humans from animals (Frankfurt 1971, 6). Thus, there is a long and persistent trend in the history of philosophy of connecting autonomy to dignified human life. We assume here that being treated as a dignified being also furthers one's well-being (e.g., through strengthening feelings of self-worth and self-esteem). This has recently been evidenced in a large questionnaire survey distributed by Goyarrola et al., which showed that the ability to make one's own decisions correlated strongly with quality of life (Goyarrola et al. 2023). The link between autonomy, dignity and well-being also appears in modern palliative care. One of the key principles of end-of-life care is to respect the patient's (relational) autonomy (Gómez-Vírseda et al. 2020), and Chochinov et al. have developed "dignity-therapy" to alleviate dying patients' stress and to help them die with dignity (Chochinov et al 2008).

The connection between autonomy and dignity is also present in legal thinking, especially in human rights jurisprudence: human rights are thought to be derived from human dignity, and one of the main functions of human rights is to facilitate and protect autonomy. As we saw above, this is especially clear in the UN Convention on the Rights of Persons with Disabilities. Indeed, it seems that the connection between a dignified life and the freedom to make one's own choices is even stronger when a person is in a vulnerable or marginalized position, as the above-mentioned principles of palliative care illustrate. How can law support the autonomy of vulnerable persons? We turn to this question next.

# The legal framework

After having analyzed the concept of autonomy and discussed some of its connections to human well-being, we turn to the legal framework for protecting autonomy. Legal means are especially important for people whose capacities of autonomy are deteriorating or who are not fully functioning, as may be the case with some older persons. As we will see in the last section of this article, autonomy retains its value for frail older adults; therefore, the question of how it could be supported becomes vital.

Curiously, personal autonomy is seldom explicitly mentioned in constitutions or lists of rights. However, it can be interpreted as being protected by the right to liberty, and it may be implicit in the Constitution, for example, through the *travaux préparatoires* or case law. For example, in the *travaux préparatoires* of the

Finnish Constitution, autonomy is said to underlie the fundamental rights listed in the law, such as Article 7, on personal liberty. Also, as regards many human rights treaties, the right to autonomy can be seen as implicit. For example, the first sentence of Article 1 of the UN Universal Declaration of Human Rights reads, [a]ll human beings are born free," and this can be interpreted as referring also to autonomy. Similarly, autonomy can be seen as included in Article 5, on informed consent, and Article 9, on respect for the previously expressed wishes of patients, of The Convention on Human Rights and Biomedicine by the Council of Europe. As we saw above, autonomy is explicitly mentioned in the UN Convention on the Rights of Persons with Disabilities (CRPD), which commits itself to respecting the right to self-determination among persons with disabilities in the preamble and Article 3, which sets out the general principles in this regard. This topic is addressed in more detail in Articles 16(4) and 25(d).

As the examples taken from human rights treaties show, personal autonomy is given particular attention at the legislative level when it is perceived to be lacking or threatened. Autonomy is also often defined negatively in terms of situations in which it is subject to exceptional restrictions. This is the case, for example, when a guardian is appointed for a person who is incapacitated under the Finnish Guardianship Act (442/1999, § 8) and when the capacity of the client must be restricted (§ 18). On the other hand, for example, the Finnish Act on the Status and Rights of Patients (785/1992, Patient Act) and the Act on the Status and Rights of Social Welfare Clients (812/2000, Client Act) are based on respect for the patient's and client's right to self-determination. The patient must be treated in agreement with this right (Patient Act 6.1§), and the wishes and opinions of the client must be taken into account in the provision of social care (Client Act 8.1 §). Both laws also contain separate provisions on the right of selfdetermination for patients and clients who are incapacitated. In the case of a patient who is incapacitated, it is assumed that the patient's legal representative, their next of kin, or another close person must be consulted before an important treatment decision is made to ascertain what treatment would best reflect the patient's wishes (Patient Act § 6.2). The same principle applies if the social care client lacks the capacity to consent. In such cases, the client's wishes must be ascertained in cooperation with their legal representative, a relative, or another close person (Client Act 9.1 §).

There are also legal instruments that enable a person to prepare for potential future incapacity. With later-life legal planning, a person can ensure that their "healthy" will is respected when they have lost the capacity to make valid decisions (Frolik 2009). For example, the Finnish legal system makes it possible to perform such legal planning by seeking a guardianship order from the guardianship authority (Guardianship Act 12 §) or by giving continuing powers of attorney (Act on Continuing Powers of Attorney, 648/2007). A continuing

 $<sup>^{14}</sup>$  Government proposal 309/1993, 42, 46.(Hallituksen esitys HE 309/1993 vp (eduskunta.fi). See also Neuvonen and Rautiainen 2015, 35.

power of attorney is a deed in which a person appoints a proxy decision-maker to make decisions if they later lose their capacity to manage their own affairs. As regards healthcare decisions, it is also possible to draw up an advance directive (Patient Act 8 §). Expressions in an advance directive tend to be either consent to or refusal of potential future treatment. However, wider advance-care planning, such as including one's views and wishes about care, is possible.

This brief examination of the legal framework thus reveals the importance of personal autonomy for modern legal thinking in two ways. One the one hand, the law is, to a large extent, silent about personal autonomy on typical lists of human rights. This can be taken to indicate that autonomy is the self-evident starting point that needs not to be explicitly mentioned; instead, it is simply presupposed to be among our basic rights. On the other hand, the law recognizes autonomy in situations when it is threatened or must be supported or restricted. The law attempts to protect vulnerable individuals' autonomy as much as possible and requires clearly defined criteria and procedures if it must be restricted. This indicates that, although autonomy does not always override other values, such as protecting the individual, it nevertheless cannot be easily discarded, and its interferences should be kept to a minimum. Indeed, the law now respects the right to autonomy among vulnerable people, such as children, older people, and people with disabilities, to such an extent that one can even speak, as Lucy Series does, of a paradigm shift in the way the legal status of these groups is understood (Series 2020). The traditional paternalistic approach has been at least partially overtaken by a way of thinking that protects the autonomy of individuals who formerly were thought to be incapable of it (Quinn, Gur and Watson 2018).

This paradigm shift fits well with the upsurge of relational understandings of the self and autonomy. If it is acknowledged that everyone needs social support to develop the capacities for autonomy, and that in practice, almost everyone relies on their close relationships in making decisions, then it is possible to think that autonomy is not only for fully mentally and physically competent persons. Even a person with severe disabilities can, with appropriate support, make some autonomous choices, even if their autonomy is not full in all respects. What is crucial here, as Joanne Watson (2017) argues, are the attitudes of the supporters. If they believe in the capacity of the supported person's self-determination, they are more likely to be responsive to the supported person's communicative efforts to express their will and preferences, and thus to enable the person's autonomy.

Rosie Harding argues that not only humans but also laws can be relational (Harding 2017, 2); that is, the law can take into account this relational nature of human beings. Is this the case in Finland? For the sufficiently competent individual, Finnish law still largely follows the traditional liberal idea of individual autonomy: individuals make decisions about their own affairs independently and they should be allowed to make decisions without undue

influence on the part of others. But especially in the context of family and social law, the relationality of individuals is considered to some extent. Examples of relational law include the above-mentioned Act on the Continuing Powers of Attorney and the above-mentioned provisions on decision-making for incapable patients and clients in the Patient and Client Acts. Furthermore, in not only legislation but also judicial decision-making, it is possible to adopt an interpretation that recognizes the intimate networks of individuals. This can be seen, for example, in some Supreme Court decisions in Finland. The Supreme Court has recognized the importance of intimate relationships, for example, in some decisions concerning the validity of a will. Although the active action of the beneficiary may be seen as an indication of the testator's persuasion, the Supreme Court has emphasized that, if a beneficiary assists the testator in making practical arrangements and, thus, seeks to assist the testator in fulfilling a will, this is not necessarily persuasion under the law.<sup>15</sup>

Of course, there are also risks in laws that take a relational stance to human beings. For example, if a person applies for income maintenance, the income of their spouse is also taken into account: the assumption is that couples living together pool their economic resources and support one another (Marriage act 234/1929, 46 §). But in reality, the applicant may have little or no access to their spouse's income (and the party who has weaker economic power in a heterosexual relationship is typically a woman). Our empirical study focuses on older people living alone, so this risk was not relevant for our analysis. However, it must be remembered that the abuse of power is an ever-present danger in all human relationships.

# Older persons' experiences of autonomy

In this last section of the article, we connect the theoretical and legal discussion about autonomy to real life and bring the voices of older persons to the fore. Writers 2, 3, and 4 of this article worked on an empirical research project that involved interviewing older Finnish persons about their ageing and autonomy. After introducing the method of this research, we discuss its findings.

#### Method

Before beginning the research project, ethical clearance was obtained from the Ethical Review Board in the Humanities and Social and Behavioural Sciences at the University of Helsinki. In addition, the ethical board of the co-operating hospital approved the plan for the study.

The data collection took place in the spring of 2017 by utilizing Service TV (STV). STV is a platform that operates like many current remote video-conferencing platforms do: the older persons themselves had functioning

 $<sup>^{\</sup>rm 15}\,\mbox{Supreme}$  Court (KKO) 2004:8; Supreme Court (KKO) 2012:103.

<sup>&</sup>lt;sup>16</sup> We thank the anonymous referee for bringing our attention to this example.

apparatuses via which to connect with other people and the service providers hosting the STV broadcasts. First, the STV coordinators in two different hospitals introduced the idea of discussion groups to their home-based clients, after which the second author of the paper held an informal information meeting for potential participants. The idea was that all those who were interested would be invited. However, the exclusion criteria was that people with severe memory loss could not take part. This recruitment process resulted in the identification of 13 women and three men who were willing to participate. Our 16 participants were divided into three groups in order to have a reasonably equal number of participants in each group. To protect their anonymity, all participants were given a pseudonym and identifying factors are omitted from the paper. All quotes from the data are translated by the authors.

The participants were born in the 1920s and 1930s and the mean age was 90 years. They lived in their private homes and were widows and widowers. They were all either veterans of the Finnish wars, their wives, or women who had served in the women's voluntary paramilitary service (after gaining independence in 1917, Finland had a civil war in 1918, fought the Winter War against the Soviet Union in 1939-1941, and then fought the Germans in 1941-1944, known as the Continuation War). The older population is remarkably diverse, including people with different abilities and support needs. Therefore, it is more meaningful to discuss the era of life they are experiencing rather than rigidly categorizing them into specific age groups (Kiuru & Valokivi 2022). People in the third age are those who are able to live independently, regardless of their chronological age. In contrast, the fourth age refers to those who require external support and/or care to manage their daily lives (MacKinley 2017). With this approach to understanding old age, the participants in this study could mainly be understood as older people in the third age, as they were able to live quite independently. Some of them seemed to be in transition from third to fourth age, as they were preparing for increased support needs in the future.

Each of the three discussion groups met 5–7 times by utilizing a STV platform. Group discussions were led by a pair of scholars whose expertise ranged from law to theology to social politics. The length of each meeting varied between 45 and 60 minutes (17 meetings in total). Each of the meetings had a pre-selected theme and a thematic interview guide. As prior research indicates, finding coherence in life is crucial to life's meaningfulness for older people (MacKinlay 2017, Ganzevoort 2010). Therefore, it was chosen as the angle at which to approach themes such as "me as aging," "turning points," and "life here and now." Furthermore, we discussed the themes "my right to choose" and "my values and worldview" because, as we argued above and as empirical studies have shown, respecting the autonomy and values of an individual promotes their experience of meaningfulness in life (Saarelainen, Mäki-Petäjä-Leinonen and Pöyhiä 2022). As the participants talked so often and openly about their important relationships, we did not need to include "the importance of relationships" as a

separate theme, as we planned. This allowed us room to let the participants choose one theme that they wished to include. This led to a formation of the theme "memories from youth." As the opportunity to remember may confirm the experience of coherence and provide joy (Ganzewoort and Bouwer 2007; Gothóni 1987), the participants' wishes were granted. All the spoken material was transcribed and formed 110 pages. To ensure anonymity, the interviewees were given pseudonyms.

Template analysis (TeA) was employed in analyzing the data. By following the structure of TeA, the material was coded openly and independently by the second and fourth authors of this paper. As the basic idea of TeA is to provide an initial thematic template derived from part of the data to support the analysis of the remainder of the data (King 2018, ch. 14), the coding and formulation of the initial themes were based on a meeting-by-meeting analysis of the first group. This initial thematic template was supplemented by findings and tones discovered from other groups. Therefore, the final template provides a full picture of the themes.

Next, we present the participants' views as they emerged in the STV discussion groups regarding the importance of remaining independent, living according to one's own values, and relationships for the exercise of autonomy. These illustrate the three different dimensions of the concept of personal autonomy that were introduced in the first part of this article. We also point out how autonomy was related to participants' well-being.

#### Results

The importance of independence (the individualistic dimension of autonomy)

As we saw earlier, individualistic conceptions connect autonomy with independence and self-sufficiency. Such connections were made also by our participants, many of whom placed a high value on personal independence and on personal capability to take care of oneself. Loss of independence was seen as a fearful thing, while the possibility of such a loss was also sometimes realistically acknowledged.

For example, Helena, who was 91 years old, gave her thoughts on the importance of personal autonomy as follows:

Otherwise, I am really happy, even though I live alone. I am free to be here, and I can do everything as I want. I don't have any kind of guardianship, and I consider it a very valuable thing.

Helena attaches great value to taking care of oneself, despite lingering loneliness. In fact, it seems that Helena describes her loneliness in terms of solitude. This type of loneliness can be framed in a positive or neutral way, as living life independently as an individual. The freedom "to do everything as I

want" is closely linked to Helena's happiness; this illustrates the connection between autonomy and well-being.

Some participants emphasized their capability to make decisions concerning their own lives. This type of trust in personal capability was especially described by those whose physical capacity was high, as it seemed that they had made no or only a few arrangements to anticipate the changes that the future might bring. For example, Olavi, 93 years old, explains the situation as follows:

Nothing else has been done than the will, nothing else like that. I can still get along by myself here, and I have not made any agreement with any of the children about anything. Actually, I'm fine, as I don't have any diseases, so it's really good to be alive, and the future looks quite nice at this stage.

Olavi's words reveal that he did not find preparations for the future relevant to his current life. He only had a will made years ago, as it was a sensible thing to do. In the group discussions, Olavi emphasizes that he is very active and takes care of his daily business, including driving a car. We assume that his strong physical health and cognitive capacity led him, as well as a few other participants, to think that there was no need to worry about making any preparations for the future. Autonomy "here and now" was more important for them. Olavi's and Helena's thoughts illustrate how self-sufficiency – "getting along by oneself" – was valuable for them and part of their idea of what autonomy means. However, Olavi also mentions his children. His words imply that, if his capacities deteriorate, he can count on his children to help him. This shows nicely how his independence is nevertheless realized in a web of relations that may later compensate for his loss of self-sufficiency.

In some other cases, the importance of independence and self-sufficiency was revealed through reflections regarding a potential loss of autonomy. Such a loss was seen as frightening. For example, Johannes, aged 94, regarded his independence as highly meaningful when he said:

And it is the great impediment, or the bad thing, that independence is lost. It is the only fear that man has and what should be feared, that you can no longer decide your affairs, about your own affairs.

Johannes here seems to equate autonomy (deciding about your own affairs) with independence, thus highlighting the individualistic dimension of autonomy. It is striking that Johannes describes the loss of independence as "the only fear that man has." Perhaps, as is so often the case in life, we only notice how valuable something is when we face the possibility of losing it.

Although the loss of autonomy was regarded as a bad thing, the possibility of such a loss was, in some cases, realistically acknowledged, and measures were taken in case this possibility is realized in the future. However, it was important

to remain independent as long as possible. The potential future shift in decision-making and its currently individual nature were highlighted in Aino's and Liisa's descriptions:

Well, I can decide things myself and know how to act, so I do all my actions. The daughter has been placed as a proxy, tentatively, but nothing else, because I decide all of my things and I'm in the condition that I still can. I do everything by myself, go to grocery store. I do all things by myself, so I haven't needed it yet. (Aino, 91 years old)

I have a power of attorney made. They'll take care of my things then if I become so dumb I don't understand anything at all [laughs]. Then, they'll take care of me... my grandchild is a law student and has the understanding needed, so I don't need to be so wise. Now, they propose things to be done in a certain way, and I either accept or disagree. (Liisa, 92 years old)

Aino and Liisa emphasized how, despite the drafting of continuing power of attorney, they still have full competence to make independent decisions. At the moment of the interview, Aino managed all her affairs independently, and she also understood that continuing power of attorney is just a precaution for the future. Liisa also emphasizes her own independence and the fact that she has the final decision-making power regarding her own affairs: she either accepts or rejects her loved ones' suggestions about how to handle things.

Living according to one's values (the procedural dimension of autonomy) Autonomy, in the procedural sense, includes the idea of authenticity: to be autonomous means living according to one's deeply held values and commitments (Frankfurt 1971, Friedman 2003). This aspect of autonomy emerged in the interviews, especially in relation to participants' thoughts regarding the end of life. It was important for them that their values would not be compromised and that their wishes would be followed at the time of death and after it. They had clearly reflected on these matters in terms of the procedural sense of autonomy, as the following quote from Aili, aged 95, shows:

In my opinion, the heavenly father has given us life, so he shall end it as well. You cannot end it [life] until it is automatically [ended by God]. At the most, you can leave your medication untaken, but no euthanasia or anything like that.

Aili has clear views as to how she wants the end of her life to go: euthanasia is unthinkable for her. This is connected to her religious commitments. She seems to find calmness in the idea that individual autonomy has certain limits, that the ultimate decision regarding the length of life can only be made by God. Many other participants as well described religious life as part of their personal values

and a source of meaningfulness. An often-expressed wish among the participants was to die in the calmness of one's home, even though the timing of one's passing could only be decided by God. Thus, it was important for them to live authentically, according to their religious commitments, until the very end of their lives. God could even be described as part of the web of relationships through which their autonomy is realized.

Autonomy in the procedural sense (i.e., in the sense of acting according to one's reflected preferences) emerged regarding the arrangements after one's death, as the following quotes by Liisa and Veikko illustrate:

Additionally, I have wishes that only the closest ones come to the grave. I wish that they will do what they find best. I always tell them that it is ok to incinerate me if that's easier. It is so hard to find pallbearers these days. If I am not so messed up, at least I don't take any drugs (to cause euthanasia) myself, and I hope I won't be given any. I have always said that I want to suffer what is given for me to suffer. (Liisa, aged 92)

At least 15 years ago, the will was made, so I have thought about it, and it has been done. It is kept safe in the deposit box. It is kept there until the funeral. It is decided who will be invited there and so on. (Veikko, aged 93)

Liisa, like Aili, expresses her wish to avoid euthanasia. This is a deeply endorsed value for her, as she describes that she has "always" thought that one must bear one's sufferings. Both Liisa and Veikko have thought about their funerals: who are the meaningful people in their lives that they want to be there, and how is to be done? These are deeply meaningful regarding one's individuality and true self, and respecting these wishes is an important aspect of respecting Liisa's and Veikko's authenticity and autonomous agency.

*Relying on others (the relational dimension of autonomy)* 

Finally, we turn to the theme of relational autonomy.<sup>17</sup> It emerged in the interviews in many different ways: the participants described how they made decisions within a web of relationships, how their nearest and dearest acted as proxies, how the web of relationships made legal planning unnecessary, and how legal planning created a sense of security.

Although the participants lived alone, they had a fairly strong network of loved ones and relationships that they could count on for help and support. This was reflected in the fact that, for example, plans for one's own future and the legal anticipation of aging, such as the drafting of a power of attorney, were planned together. Many had discussed these issues and made decisions with the support of their families and other loved ones. Eila and Aino described the preparation of their continuing powers of attorney:

<sup>&</sup>lt;sup>17</sup> This sub-chapter is a modification of an earlier discussion of these results by Mäki-Petäjä-Leinonen (2023, 349-364).

We have made an agreement that, if I reach that condition, then one of the grandchildren will take care of things, and he also has one substitute for my children in it, but if this poor head will still be in this condition, then there will not be a big need for help. (Eila, 95 years old)

Yes, my daughter was over 40 years in the bank, and she made the paper there that is still pending as long as it needs to... but then (if needed) it has to be verified by the magistrate when the doctor states that I can't handle my things. (Aino, 91 years old)

The descriptions of Eila and Aino show how relationality and relational autonomy can be present both when taking proactive legal actions and when selecting individuals as potential substitute decision-makers. When, for example, continuing powers of attorney are drafted in advance in the event that, one day, a person is unable to manage their affairs, Eila and Aino highlight that they have made such plans within their close web of relationships. Eila described how "they" had made such arrangements within the family, and Aino, in turn, described how her daughter had prepared the documents. In addition, Eila described how she had appointed one of her grandchildren as her proxy. In the best case, these kinds of preparations enhance the experience of meaningfulness in life in old age. For example, the self-actualization of Eila and Aino was increased because, with the support of the family members, they were free to make decisions about the future.

Relationality was also reflected in the fact that it was important for the participants that loved ones, not outsiders, take care of their affairs if they lose their ability to cope independently. Liisa and Aili described their situations as follows:

Yes, we have talked, and I have given a power of attorney to her so that, if I lose my mind, she will take care of me and not an outsider. And, even today, she takes care of all the banking because I can't go to the bank. Yes, my daughter takes care of all my business, just a way I want. (Liisa, 92 years old)

My younger daughter, she is the kind that brainstorms, so she takes care all of my things. I know nothing. I have given her power of attorney. She takes care of everything. Everything is playing well. She is fair and honest. Then, they have divided those jobs so that each child has their own job. Then, they walk me out during the day and always for a set period of time. (Aili, 95 years old)

The narratives offered by Liisa and Aili reflect the fact that they seem not only confident in but also quite proud of their close relationships and safety net. There was no need to worry when a strong network of loved ones was there to

provide support. This also seemed to have a positive effect on their experiences of their own well-being. This illustrates Schnell's ideas that interpersonal relationships and the experience of one's own well-being, together, form a central building block of meaning in life (Schnell 2009). Having a trusted web of relationships gives peace of mind, as one knows that everyday decisions can be made by one's children if needed.

On the other hand, some participants in the study raised an issue that has been recognized in previous studies: many people trust their relationships even to the extent that legal planning is not considered necessary; power of attorney or other legal instruments are not required, as the next of kin can handle matters without authorization (Nikumaa and Mäki-Petäjä-Leinonen 2020, 694). Helena described her situation as follows:

The closest one is my younger son. With him, I've been talking, and all the practical things have been clarified. He already has the key. He can get to my apartment, and then, he can take care of all the things as needed... I haven't read the will, and nothing else has been done. However, in practice, I know that my youngest son will take care of it when the time comes. Then, the youngest son will take care of everything. (Helena, 91 years old)

Helena thus highlights the importance of supporting relationships. The trust that she has in her son seems to provide a sense of security and peace. She relies on her son's support, both now and in the future, so "nothing else has been done" as a precaution. It is, of course, the case that the vast majority of people live out their lives without decisions being made on their behalf by a proxy. However, when some older people develop memory disorders that impair their legal capacity or, in some other way, lose their ability to make independent decisions, a question arises regarding the extent to which older people are informed about their means of legal planning. For example, it is not always known that, in Finland, the bank may find it difficult to do business if the power of attorney is not in order. This, in turn, may lead to the otherwise unnecessary appointment of a guardian under the Guardianship Act (442/1999).

Further, legal planning conducted within trusted relationships seems to have the effect of supporting the sense of coherence and security among the participants. When planning for the future is complete, there is no need to worry about forthcoming life events. For example, Taimi, aged 91, described her experience with drafting a mutual will with her spouse by saying the following:

There are many things that are left to the last minute. People imagine that they will live forever and things like wills and inheritance will be left undone. But my husband was not such a case. Even though he was old

and born in the sauna, he knew how to take care of all things so well that I have no worries about our legacy. It has been taken care of.

The above quotation reveals that, often, people seem to leave legal planning to the last minute, but when they take action in a timely fashion, there is no need to worry. Taimi and others found that it was crucial to draft their legal papers before an actual need to do so arrived. This is a way of furthering coherence in one's life: one can count on life's continuing according to one's own plans as one's own capacities for expressing or executing those plans cease to function properly.

#### Conclusions

The task of our paper was to analyze the concept of personal autonomy and its connection to well-being, as well as Finnish legal instruments via which to support the autonomy of older persons. Furthermore, we wanted to let older people themselves tell how they experience autonomy in the context of old age and legal planning. Thus, we illustrated our theoretical and legal analysis with some real-life examples from older persons in Finland.

What conclusions can be drawn from this multidisciplinary study? Although the empirical material was relatively small, it supports the suggestion made in the first part of our article – that autonomy is a complex concept that includes individualistic, relational and procedural dimensions. The material also shows the value of autonomy for older people. Being independent and getting along by oneself seemed to be extremely important – in the memorable words of 94-years old Johannes, the loss of independence was the "greatest fear" man has. The indispensable role of relations in sustaining and supporting older persons' autonomy came also very strongly to the fore. Indeed, the interviewees talked spontaneously about their relations so often that there was no need to make this a separate theme for discussion. Furthermore, the connection between autonomy and well-being was reflected in the empirical material: being able to decide things for oneself, especially regarding the approaching ending of one's life, gave the interviewees happiness, peace of mind, and a sense of coherence of life.

Our study also indicated that legal planning that was done in advance within a trusted network of relationships provided security, calmness, and meaningfulness for the participants. This type of advance planning seemed to promote wellbeing in the current moment, when older people were still doing relatively well on their own. However, the idea that, even with decreased decision-making, their autonomy would be supported through their proxy gave them tranquility regarding their future as well.

All in all, very positive narratives about close relations' role in older persons' lives emerged from our interviews. Yet some caution is in order when interpreting these narratives. Perhaps conflicts with family members or misuses

of power by proxy decisionmakers or other negative experiences were not mentioned because the participants wanted to present their life story in as good a light as possible in front of the other participants. This is a shortcoming of the method of group discussion that we acknowledge. Individual interviews might have disclosed less positive examples about the role of close relations in older peoples' lives.

Although our material does not warrant drawing any conclusions as to whether older men and older women think differently about autonomy, it raises some interesting questions in this regard. In theoretical literature (e.g., in Mackenzie & Stoljar 2000, 3), the individualistic conception of autonomy has been associated with masculinity. In our empirical material, men were a minority, but they indeed highlighted independence somewhat more than women did, and they had made less arrangements regarding the possible loss of independence. Is this because they were physically in a better condition than our women participants – maybe the planning was not topical for them? Or does the lack of planning, and strong reliance on self-sufficiency, reflect the cultural expectations that men must be independent? Do these expectations make it hard for them to ask and accept help, even if they would want and need it?

These would be interesting questions for future socio-legal research. Nevertheless, our study suggests that authorities should more actively promote knowledge about the legal means of protecting older persons' autonomy, so that lack of later-in-life legal planning is at least not due to insufficient public information, guidance and counseling. Without legal planning in advance, there is a danger that one will not be able to live according to one's wishes at the last stages of one's life and to be able to die with dignity.

The law could also better recognize the relational nature of humans. The individuals' close web of relations is already taken into account to some extent in legislation, especially in family and social law and its interpretation. Examples of relational law are, for example, the above-mentioned Act on Continuing Powers of Attorney and the provision of section 43 of the Social Welfare Act (1301/2014) on mapping the customer's close network. On the other hand, for example, the interpretation of the Guardianship Act could take greater account of the importance of the client's close networks and also encourage guardians to provide more support to their sufficiently capable clients in decision-making (Mäki-Petäjä-Leinonen 2022, 232-233). Also labor law could better accommodate the fact that many middle-aged workers not only take care of their own children, but also support the agency of their aging parents. Working-life should take into account these multiple care-commitments and be sufficiently flexible (by e.g., allowing temporary leaves or part-time work if the care of one's parents requires it). This illustrates how the realization of older persons'

<sup>&</sup>lt;sup>18</sup> In Finland, a working group of the Ministry of Social Affairs and Health proposed amending the Health Insurance Act (1224/2004) to extend the provision on special care allowance to cover short-term or temporary loss of earnings caused by an insured person's participation in the hospice care of a seriously ill family member (Sosiaali- ja terveysministeriön raportteja ja muistioita 2021, 60-61).

autonomy depends not only on their close web of relations, but also on larger societal structures and practices.

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