

Essay

Learning from Elders about Autonomy, Meaningfulness, and Relationships

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Abstract: In this essay, we appeal to conceptual and empirical research to establish that autonomy and meaningfulness, when understood concretely and realistically, remain possible for frail and dependent elders. Contrary to ageist cultural attitudes, relationships render frailty and dependence compatible with the exercise of autonomous agency and with a life of meaning. This conclusion is important not only for the goal of supporting frail elders but also for developing a realistic understanding of the way relationships and spirituality are required for autonomy and meaning in the life of any human person, regardless of what state of dependence or independence they may be in. Each of us develops and continues to exist in radical dependence on others. Seeing the way autonomy and meaning manifest in the context of frailty and dependence thus helps us better appreciate what these crucial aspects of being human mean for all of us. In other words, we can learn important lessons about autonomy, meaningfulness, and relationship from the experience of our elders, and in particular from those who experience significant frailty and dependence.

Keywords: autonomy; meaning; dependency; frailty; dementia

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1. Introduction

According to the classical liberal view of autonomy, a person is autonomous if they are capable of making and acting on decisions that are aligned with their own values and preferences without being unduly influenced by factors external to the self. This view effectively rules out autonomous choice and action for frail and dependent elders who suffer from serious cognitive and social incapacities due to dementia or other illnesses, since they lack the capacities requisite for such choice and action. However, important scholarship has shown that frail elders in fact retain the ability to exercise autonomous agency, so long as autonomy is understood more realistically than it is in the classical liberal view. Concrete accounts of autonomy that are sensitive to the context of aging and frailty show that autonomous agency remains possible even for seriously impaired and dependent individuals. In the case of many such individuals, illness has modified but not effaced the capacities needed for such agency. With the right sort of relational attention and support, frail elders can continue to express their autonomy. Frailty also seems to threaten the ability of individuals to find meaning in their lives by making it impossible for them to engage in activities that previously gave life meaning. However, recent studies of meaningfulness in frail elders show that relationships provide a source of enduring meaning even in a context of seriously diminished capacity. Relationships, then, are centrally important for nurturing both autonomous agency and meaningfulness in frail and dependent elders. Given our profoundly social nature, this insight concerning the centrality of relationships extends to human beings generally, regardless of our state of relative capacity or incapacity. An examination of autonomy and meaningfulness in the context of frailty and dependence thus reveals important features of human existence that are often overlooked when autonomy and meaningfulness are viewed from a vantage

point of ability and independence. In turn, this revised understanding has the potential to help combat ageist cultural attitudes. We offer this paper as a stimulus to reflection and rethinking concerning the place of autonomy and meaningfulness in human lives, however robust or diminished in capacity they may be.

Before entering into the main argument, we need to begin by clarifying some important terms. Across the human lifespan, we experience periods of heightened dependence on others. Old age is one such time in life, as general wear and tear, greater susceptibility to disease, and decreased regenerative capability lead to an accumulation of deficits, increasing the likelihood of dependence. In medical contexts, dependency is considered an outcome of temporary or chronic functional disability, which necessitates reliance on others to perform tasks that could previously be performed alone (Timonen and Lolic 2020). There is considerable overlap between concepts of dependence, disability, and frailty; however, in recent years researchers have favored the conceptualization of frailty to describe the state in which independence is most compromised. Frailty is often defined as an age-related state of decline and vulnerability, characterized by decreased physiological reserves and function across multiple organ systems, leading to an increased vulnerability to future adverse events (Fried et al. 2001; Mitnitski et al. 2001).¹ Gilieard and Higgs argue that this increased susceptibility to poor outcomes marks frailty as the boundary of the “fourth age”, which is a time of life, typically after the age of 80, characterized by incapacity and frailty when care services are required to retain proper functioning (Gilieard and Higgs 2010; MacKinlay 2014). The fourth age embodies the socially understood and feared time of life in which individuals are permanently impaired, dependent, and cease to be cognizant, functioning agents (Higgs and Gilieard 2014). This is the state that we wish to explore in the following paper, as it epitomizes the perceived loss of autonomy and meaningfulness that comes with a diminishing capacity in old age. We will later use the case of dementia as an illustrative condition in which capacity is significantly diminished and sufferers could be described as embodying characteristics of the aforementioned fourth age.

2. Autonomy and Meaningfulness in the Context of Frailty and Dependence

2.1. The (Ir)relevance of the Liberal Conception of Autonomy

Autonomy, the ability to choose what to do and how to live in accordance with our own most deeply held values and beliefs, is a key part of what makes us human persons. One major tradition of thinking about autonomy stems from the liberal social and political thought of Enlightenment thinkers John Locke, Immanuel Kant, and John Stuart Mill. The liberal view depicts autonomy as the ability of free, independent, rational agents to form and execute decisions on the basis of their own determinate and consciously understood preferences, values, interests, and conception of the good life.² To be autonomous, in this sense, is to be able to act without undue influence from others, in particular from the State and from people in positions of power who might otherwise impose on one their own vision and conception of the good. Isaiah Berlin referred to autonomy in this sense as negative freedom—in slogan form, the “freedom to be left alone” (Berlin 1969; Young 1986). Autonomy in this sense has been important in securing patient rights, such as the right to refuse unwanted life-sustaining treatment. It lends legal and political power to individuals vulnerable to having their wishes and interests overridden by the paternalistic impulses of healthcare professionals and institutions. This view depicts human persons as “social and moral atoms” who can be understood without reference to their social and historical context. As Agich notes, “Relationships are considered only when they involve intrusion into the solitude of individuals” (Agich 2003).

The classical liberal view tends to assume a vision of human moral agents as fully informed, competent, self-sufficient, monadic, isolated centers of decision-making. Such a vision has been roundly critiqued in the literature on autonomy, by communitarian and feminist thinkers among others, as an abstract idealization, out of touch with the way the vast majority of actual human beings make most of their decisions. Besides being unrealistic, the classical liberal view of autonomy contributes to harmful cultural attitudes

such as ageism and a general aversion to dependence. From the time we are conceived all the way through to the point at which our lives end, human beings are massively and deeply dependent on others and on a shared social world for our ability to survive and to exercise our own agency. However, the ways in which dependence manifests in frail elders, many of whom suffer from chronic illness, contrast more starkly with our notions of autonomy as self-sufficiency and independence than do our everyday experiences of dependence. Ageism and dependence-aversion combine with our anxieties about suffering and death to produce a feeling of revulsion at the dependence we observe in frail elders. We treat the frail elder as “other”, separating them off (both mentally and physically) from the healthy normalcy of everyday life. In turn, these cultural attitudes, derived in part from the conception of autonomy as independence, self-reliance, or self-sufficiency, have a negative impact on elders’ self-understanding and sense of self-worth.³

Despite its flaws, the liberal understanding of autonomy as independence or negative freedom continues to impact the public imagination and discourse as well as bioethical discussion and debate. Agich (2003) demonstrated that to be of use in considering the situation of many frail elders, this conception of autonomy must be enriched and supplemented by relating it to the concrete conditions of actual autonomy in long-term care.⁴ In the context of frailty and concomitant dependence resulting from serious illness and/or old age, the traditional liberal conception verges on total irrelevance. Various cognitive, psychological, and social impairments make it impossible for frail elderly individuals in need of long-term care to exercise their agency independently (Agich 2003).⁵ Diminished capacities due to illness combine with relational, environmental, and institutional factors to dramatically limit both the scope of choices available to frail elders and their abilities to form and carry out decisions.⁶ Even at our best functioning, we cannot foresee with certainty what the effects of our choices will be, and we have an imperfect understanding of our own best interests (even if we know them better than anyone else). How much less appropriate it is to apply the standard of an ideal rational decision-maker to individuals living with dramatically impaired functioning. The irreconcilability of the liberal conception of autonomy with the lived realities of frail and dependent elders might lead us to infer that such individuals no longer possess autonomous agency and that for this reason decisions ought to be made on their behalf by duly empowered others (e.g., substitute decision-makers, physicians, long-term care staff). Alternatively, recognizing the deficiencies of the liberal view that implies a lack of agency in frail elders, we might instead look for a more adequate account of autonomous agency compatible with dependence resulting from diminished capacities. We believe the second option is strongly preferable. For one thing, concluding that frail, dependent elders can no longer exercise autonomous agency removes one important basis for insisting on respect for such individuals since many influential ethical theories draw a close connection between respect for persons and the possession of autonomy. For another, and as we hope to indicate in what follows, the conclusion that frailty and dependence necessarily entail the loss of autonomous agency is simply false. In the remainder of this section, we outline Agich’s approach to actual autonomy in the context of long-term care as an important example of a more adequate account.⁷

2.2. Agich’s Framework for Actual Autonomy

In attempting to understand autonomy concretely, and in a way that is relevant to the everyday lives of individuals in the various contexts and situations of long-term care, Agich attends to the phenomenology of agency as it occurs in such settings. In everyday life in long-term care, autonomous agency manifests not primarily in discrete moments of fully conscious, rational choice between momentous alternatives, but rather in the ongoing processes of adaptation, identity-formation, and world-making. At a fundamental level, autonomy, as Agich sees it, involves the ongoing shaping and reshaping of our self-identity and sense of meaning, place, and direction in response to the changing circumstances in which we find ourselves. Decreased capacities due to illness can pose significant threats to one’s self-identity. They require the impaired individual to engage

vigorously in the work of reconstituting the meaning structures of their life (Agich 2003). Agich thus makes identification, understood as “the ability to reflexively recognize as one’s own the constituents of an action”, the core feature of autonomy (Agich 2003).⁸ In this view, a person’s actions and choices are autonomous if they cohere or are consistent with the person’s self-identity. The individual need not explicitly and reflectively judge their actions and choices to be coherent; “the essential requirement is that they be lived and experienced as one’s own, cohering with the sense of one’s developed self”.⁹ Autonomy in this sense is perfectly compatible with dependencies of various kinds, though it can only flourish with adequate attention and support from others.

Human beings form self-identities not in isolation but through interaction and interrelation with others. Throughout his study, Agich highlights the profoundly social nature of human beings. Agich is not alone in this effort; many others have defended the ongoing existence of autonomy in the midst of impairment by emphasizing the ways in which actual autonomy depends on social support and connection (Collopy 1986; Taylor 1979; Thomasma 1983; O’Neill 1984). Human selves emerge through a developmental process that would be impossible without the formative influences of social structures such as family, friendships, and various interactions within the broader community with its traditions and culture.¹⁰ To give just one (important and far-reaching) example, much of our conscious cognition and emotion takes a linguistic form, but language must be learned through interaction in a community with others. A wide range of abilities are required for an individual to act effectively and to produce desired and intended effects in the world (agency). These skills of thinking, willing, and translating deliberation and intention into action not only develop through an extended series of social interactions, but their ongoing maintenance and growth also depend on continuing interactions with others. Affective bonds with close relations play a significant, but often ignored, role in the identity-formation and ability to function of the autonomous self.¹¹ Agich concludes,

The fundamental meaning of the autonomy of a person is thus bound up with that person’s relationships with others Far from being isolated centers of independent decision making or action, human persons are agents in the everyday world precisely insofar as they are sustained by a complex web of interconnections and relationships with both past and present others. The concrete reality of autonomy, therefore, bears little or no resemblance to the abstract picture provided by the liberal theory. (Agich 2003)

These points apply to human autonomous agency generally, but have particular significance for the goal of nurturing and supporting autonomy in frail and dependent elders.

It does not suffice to infer from a frail elder’s diminished capacities that they no longer possess autonomous agency since they could continue to exercise such agency with adequate support. Agency can be undermined, for example, by a failure to provide appropriate choices. If the only activities available in a nursing home are Bingo, crafts, or sitting in front of a blaring television, and these options are “seen by a particular elder as meaningless or even offensive, then the very act of affording the choice . . . could diminish, even though subtly, the elder’s sense of self-worth and magnify the alienation” (Agich 2003).¹² If an elder cannot identify with the choices provided, if the choices offered “negate the integrity or self-worth of the person”, and if no attempt is made to provide choices the elder could identify with, then autonomy is inhibited by the way life is structured by others, rather than by the loss of capacity itself (Agich 2003). Practices historically common in long-term care homes have the effect of infantilizing and depersonalizing elders. Inappropriate use of physical restraints and policies that prevent elders from freely forming relationships with others or otherwise control social interactions (for instance, by assigning roommates without considering the elders’ preferences) inhibit the exercise of the autonomy that remains to elders in ways that are significant given the narrowed physical and social world of individuals who must live in long-term care homes. Staff who focus on task-centered, custodial care (“bed and body work”) without pursuing or even

investigating the elder's sense of well-being make the elder "the object of a style of care that functionally compromises the conditions needed to sustain autonomy" (Agich 2003).¹³ Agich insightfully points out that we further undermine elders' autonomy when we treat them as mere passive recipients of care, without considering the responsibilities, obligations, and virtues that continue to accrue to them as fellow members of the shared social world. The (unintended) effect is to further the social alienation of individuals already suffering from isolation and deprivation of social roles and relations. Conversely, by seeking to understand what is truly important to frail individuals, by striving to offer choices that cohere with their self-identity, and by engaging with such individuals as persons with unique life histories facing unique challenges due to illness and disability, we can nurture autonomous well-being even in contexts of increased dependence.¹⁴

As Agich and others have shown, attention to the concrete conditions of life in long-term care, and to the ways in which autonomy develops and can be sustained or undermined, leads to the conclusion that autonomous agency is entirely possible for many frail and dependent elders. Such agency is possible, however, only with adequate support from others, and within the context of a social world that permits the ongoing expression of autonomy. Whereas autonomy according to the classical liberal conception may not remain for individuals with seriously diminished capacities, this idealized conception of autonomous agency arguably gets it wrong for most human beings most of the time. Understood more realistically and relationally, the actual autonomous agency that is important and available for each of us continues to be both accessible and important for frail and dependent elders. In the following section, we show how recent studies of meaningfulness as experienced by frail elders reach a similar conclusion: lives of meaning remain possible for individuals suffering from diminished capacities due to illnesses of old age, provided that meaningfulness is understood properly.

2.3. Cultural Valuations of Meaningfulness and Their Discordance with Frailty

As interest in meaningfulness and meaning-making grew in the fields of psychology and health, many attempts to define the ambiguous term emerged (Park 2010). Roy F. Baumeister (1991) defined meaning as "shared mental representations of possible relationships among things, events, and relationships. Thus, meaning connects things". Meaning-making involves telling stories that organize independent events into a coherent whole to provide an overall sense of purpose for the individual (Hartog et al. 2017; Baumeister 1991). Meaning has a critical influence on an individual's life, especially when confronting stressful life events. Park and Folkman proposed a model of meaning-making in the context of highly stressful experiences and described meaning at two levels (global and situational),¹⁵ suggesting that people have orienting systems that provide cognitive frameworks for interpreting situations. Meaning-making, then, is the process whereby individuals attempt to align how they interpret the situation in light of their values. When successful, meaning-making can lead to outcomes referred to as "meanings-made". Meanings-made can include acceptance, a sense of having "made sense" of the situation, reattributions and causal understanding, perceptions of growth or positive life changes, a changed identity or global beliefs, and reappraised meaning of the stressor or sense of meaning in life (Park 2010). Ultimately, Park and Folkman posit that the meaning-making process can result in better adjustments to stressful life events including chronic illness (Park 2010).

Looking at meaningfulness for persons with dementia (PWD) specifically, Isene et al. applied Tatjana Schnell's (2009) definition, according to which meaningfulness is "a (mostly unconscious) evaluation of one's life as coherent, significant, oriented and belonging" (Schnell 2009), whereas "meaning-making is the process of searching for a sense of meaningfulness in life" and is widely accepted as a central human concern (Isene et al. 2021). For Schnell, coherence is the experience that one's goals, acts, and perceptions are consistent with each other. Significance is the perception of our actions as received by others and any consequences associated. Orientation refers to having a purpose or direction and belonging is the experience of being part of something larger than oneself (Schnell 2009). The areas of

cognition, significance, orientation, and belonging represent potential struggles for PWD since a crisis of meaning is triggered when the sense of coherence or continuity is violated by diminishing cognitive ability. However, the qualitative study conducted by Isene et al. suggests that persons with severe dementia still engage in the process of meaning-making because experiences of coherence, significance, orientation, and/or belonging can be identified in the everyday interactions that PWD have with others (Isene et al. 2021). Every human person, with or without dementia, engages in a process of meaning-making to experience meaningfulness in the spaces of life we occupy. However, these processes of meaning-making are heavily shaped by the environmental and social context that we live in, as will be explored in the next section.

Just as cultural attitudes about autonomy shape our expectations about the ability to exercise it in individuals whose cognitive and social capacities have declined, so do common understandings of what makes life meaningful inform what we think about the possibilities for a meaningful existence in the context of frailty and dependency. Much of the philosophical literature on life's meaning articulates the notion that decision-making and attaining goals through concerted action are central to living a meaningful life (Metz 2002). For many theorists, making decisions, adopting purpose, and acting to accomplish goals are essential for a meaningful existence (Metz 2002). For example, subjectivists argue that "life's meaning consists in being satisfied with one's choices or absorbed by one's activities . . . life's meaning is a function of inclinations, for example, desiring something and getting it" (Metz 2002). Kantians place value in rational agency as a prerequisite for living a life of meaning since they believe that only rational beings can make decisions to live according to principles. Max Weber's sociological theory of the Protestant work ethic articulates the value attached to productivity and efficiency in one's meaning in life. He credits the Protestant, particularly the Calvinist, discipline and vigorous pursuit of asceticism and production for the success of the early stages of European capitalism. The idea that meaningfulness is strongly correlated to one's productivity laid the foundation for Marxism, which views humans as innately productive and social beings who find meaning through exercising productivity and creativity. When either is lost due to diminished capacity, meaningfulness is lost for the individual. Western societies have ascribed to a capitalist economic model for many years, leading to a state of advanced capitalism, and yet many have simultaneously retained a deep entrenchment of Marxist ideals concerning individuals living together under this system. The maintenance of social systems relies on the people within them to prioritize the aims that are consistent with its ideologies and institutions. Therefore, an advanced capitalist society depends on people believing that it is important to pursue their own self-interest, that the accumulation of capital is a crucial aim in life, and that competition between people is necessary and good (Kasser 2010). A recent 2019 study by Butler further illuminated this phenomenon, showing how an ingrained sense of capitalistic values, such as self-interest, interpersonal competition, consumerism, and financial success leads to advanced capitalism-specific socialization in people living under this system. Features of this socialization include hyper-individualism, materialism, and a market-driven identity highly focused on status, success, and self-image (Butler 2019).

Overattachment to capitalistic values and materialism can lead to negative impacts on mental health and well-being, especially when a person attributes meaning and status to their life on the basis of the money and possessions they can acquire (Butler 2019). The negative impact on well-being is magnified in frail individuals who cannot fully participate in a capitalist society due to diminished capacity. According to MacKinlay, who explored life's meaning for baby boomers, materialism, outward appearance, financial independence, and autonomy are valued greatly by the cohort. Therefore, the development of frailty and its impacts leave many feeling that their life no longer holds meaning. "Rational suicide" is then seen by baby boomers as a dignified choice since they only want to live with health and without burdening others (MacKinlay 2014). This sentiment has inspired the work of Harvey Chochinov in dignity therapy, a psychological intervention designed to

address many existential, spiritual, and psychological challenges facing those with life-limiting illnesses (Chochinov 2014). The focus on productivity as a measure of worth and meaningfulness has persisted for decades with little change in how we view individuals who are frail and dependent on others. As a woman diagnosed with early-onset dementia poignantly notes, “the diagnosis of dementia exiled me from my former self—my super-capable and high-achieving career-driven self . . . I have been cast out, becoming liminal to society, which values normality and competence. I am now isolated by stigma. This stigma results from the end-stage stereotype of dementia, which depicts me as sub-human . . . ” (Bryden 2018). This experience of intractable and irremediable frailty, embodied by late-stage dementia and previously described as the “fourth age” is highly feared and othered by everyone, but particularly by elderly people who wish to retain their independence and functionality for as long as possible. In fact, loss of the ability to participate in meaningful activities and to perform activities of daily living are cited as the main reasons individuals requested medical assistance in dying in 2020 (Government of Canada 2020). Our cultural tendencies to evaluate a person’s value in life based on their productivity is concerning as it influences our beliefs about who is capable of experiencing meaningfulness; those with diminished cognitive or physical capacities are often deemed incapable based on this widely held understanding. We argue that this depiction of meaningfulness, which suggests that humans will ultimately transition into a meaningless existence as we age and become more frail, is flawed. Frail elders or those with diminished capacity do not necessarily live worthless lives. Recent studies indicate that persons with diminished capacities continue to engage in processes of meaning-making. In fact, we will argue using the case of dementia that it is through relationships that meaningfulness is experienced even in the context of seriously diminished capacity, frailty, and increased dependence on others.

2.4. Relationships as Central to Meaning-Making in Dementia

Traditionally valued sources of generating meaningfulness that prioritize achievements and productivity are incompatible with the realities of those experiencing diminished capacity. However, many PWD maintain a sense of meaningfulness through experiences that can be described as “spiritual,” even in the context of seriously diminished functionality. Spirituality can be an avenue through which the process of meaning-making according to Park and Folkman is carried out. Faith in something greater than oneself can provide a sense of meaningfulness to PWD by assigning a compatible situational meaning to their fundamental beliefs, values, goals, and expectations.¹⁶ For example, someone experiencing cognitive impairment might apply a belief that the illness is a part of “God’s plan” or that God will use the experience of illness to achieve certain benevolent outcomes, allowing them to cope and ascribe meaningfulness to the challenging situation. Spiritual practice is more likely to be retained if faith or religiosity was a large part of a person with dementia’s life prior to diagnosis, consistent with continuity theory in which people attempt to maintain long-standing social patterns of living and coping that they find uniquely their own when adapting to and finding meaningfulness within the context of serious illness (Kevern 2015; Menne et al. 2002). We will demonstrate below that spirituality, meaningfulness, and relationality are inextricably linked. The process of meaning-making in PWD is facilitated primarily through relationships with others, involving an adaptation of personal identity to achieve global meaning and a reframing of events to achieve situational meaning.

Relationships play a crucial role in the maintenance of personhood for PWD, which many experience through fellowship with God and others. Personhood/personal identity is a key part of Park and Folkman’s meaning-making model, according to which an acknowledgment of one’s own fundamental beliefs, values, goals, and expectations that have been constructed in early life and modified by personal experiences is required to operationalize global meaning in the interpretation of a given situation. Recent research has suggested that for PWD, the process of meaning-making often involves a significant adaptation/adjustment of personal identity, which is facilitated through relationships.

Meaningful relationships gain even more importance for PWD as personal memories fade, leading to an increased reliance on family, friends, and community input to reinforce beliefs about the self (Kevern 2015). Timonen and Lolich's work suggested that caregiving activities among friends and family may even inspire older adults experiencing dependency to reframe their dependent state in positive terms based on their relationships with others. For example, where older adults felt cared for by loved ones, they proudly stated their status as a "cared for individual" (Timonen and Lolich 2020). In this way, PWD were able to orient and maintain their identity through their role in relation to others, achieving a positive reappraisal of their identity and a sense of having "made meaning" of their illness. Christine Bryden, a woman diagnosed with dementia at 46 years old, described her experience with religion, faith, and dementia in several publications. Despite cognitive decline, she retained a sense of being an embodied, relational agent capable of experiencing meaning in the present moment. Bryden noted that existence in the present moment, apart from an existing narrative for herself or others, allowed her to lean into her relationship with God. Through this spiritual connection, she adapted her self-identity to account for a deteriorating sense of self by emphasizing God's presence within her, forming a sort of joint identity with the divine, which was mediated and enhanced in fellowship with others:

I will simply "be" and allow God to work in my journey living with dementia. In this journey, in this personal experience of a life lived with dementia, I travel toward less of me, and more of him. And he is present in you, in our fellowship . . . my personhood exists in relationship with you and with the divine. (Bryden 2018)

Bryden's connection with God was essential to her sense of personhood, which is retained despite adaptation to her experience of cognitive impairment. This brief quote demonstrates several "meanings-made" (in Park and Folkman's terminology), including acceptance, a feeling of having "made sense" of the situation, a perception of growth, and a changed identity, all facilitated through a relationship with God and others.¹⁷ Bryden also claimed that her personhood is maintained through the support and affirmation of the Church, which in turn, reinforces the sense of meaningfulness and purpose experienced by other Christians:

By [the church] showing me his healing power, my personhood in Christ is affirmed and validated, and the result can be transformative. I need to be heard and to be listened to, so that in this way you can demonstrate that my life—like yours—has purpose and meaning. (Bryden 2018)

Another prominent author examining this topic, John Swinton, reinforced Bryden's assertions: "[B]eing a person is something that we do together. It is not simply a matter of individual capacities" (Swinton 2021). Connecting on the basis of shared humanity allows for the development of secure communities in which those with diminishing identities can continue to grow and experience authentic relationships, whether in faith-based or secular spheres (Zournazi and Vanier 2016). Furthermore, relationships with others can facilitate a reframing of events to ascribe a positive situational meaning to the experience of dementia. Working within a faith community, MacKinlay emphasized how relationships can play a crucial role in the sustained process of meaning-making for PWD. The practice of spiritual reminiscence¹⁸ was applied to process emotions, reframe events, and come to new understandings of meaningfulness and purpose for PWD. Through spiritual reminiscence sessions with small groups, facilitators found that the majority of participants identified relationships with family, friends, and other participants as their greatest source of meaning that persisted despite cognitive decline. Some participants even noted that relationships with deceased parents or loved ones were significant sources of meaning in the present day. Acknowledging the importance of these relationships to PWD could constitute a positive appraisal of the lack of temporal orientation in dementia, which actually allowed for a greater sense of meaningfulness in participants. Relationships are frequently described as synonymous with meaningfulness as individuals become more frail and dependent on others and are unable to pursue previous sources of meaning, such as hobbies or

work, as in the case of PWD (MacKinlay 2015). Relational connectedness seems to be the key to experiencing meaningfulness for all humans, and examining the particular importance of relationships to those with dementia can help us evaluate the true sources of meaningfulness in all of our lives. As Hughes, Louw, and Sabat suggest, “people with dementia have to be understood in terms of relationships, not because this is all that is left to them, but because this is characteristic of all of our lives” (Hughes et al. 2006).

3. Learning from Our Elders about Autonomy and Meaningfulness

Scholarship on personal autonomy and on meaning-making converge on the centrality of relationships for promoting the ongoing abilities of frail and dependent elders to exercise autonomous agency and find meaning in life in the context of limitations and incapacities that arise from advancing illness and disability. Agich and others have shown that autonomous agency, when considered concretely and in terms of identification, is compatible with dependence and with cognitive and social deficits associated with illness and disability due to old age. With appropriate relational and institutional support, frail elders can continue to make choices and identify with a way of life they can recognize as their own. Relatedly, several recent studies on meaningfulness in the context of frailty—and for PWD specifically—demonstrate that important sources of meaningfulness remain available for individuals unable to engage in activities that previously gave life meaning. This research consistently shows that relationships (to God, to others) act as a deep well from which people can draw meaningfulness despite even serious frailty and dependence.

In this second part, we claim that these findings about autonomous agency and meaningfulness should not be understood as limited to the case of frail and dependent elders. Rather, they manifest important truths about the nature of personal autonomy and meaning that are relevant to human beings at all stages of development and in any state of relative capacity or incapacity. To use a metaphor from chemistry, it is as though radical frailty and dependence have the effect of distilling out the “essence” of these core aspects of human existence, enabling us to see more clearly the powerful agent always at work in both human autonomy and the experience of meaningfulness, but usually relatively hidden or diffuse in the “solution” of normal everyday existence when we are in good health. Relationships make autonomous agency and meaningfulness possible for all of us; this is a lesson we need to learn from the experience of illness, incapacity, and dependence in our elders.

Lessons on Dependence, Autonomy, and Meaningfulness

The very process of attempting to categorize a certain group of people as “frail and dependent elders” is fraught with difficulty because both frailty and dependence are complex, multi-factorial concepts. Recall the definition of dependence stated toward the beginning of this paper: “In medical and nursing contexts, dependency is generally understood as an outcome of a temporary or chronic functional disability where an individual is unable to perform a task that they could previously perform alone” (Timonen and Lolic 2020). Accordingly, a person can be relatively dependent or independent in as many ways as there are “tasks” that we can “perform”—an endless variation ranging from cooking and feeding ourselves to helping a child with homework to providing insight into community planning and development to participating in worship. To see how difficult it is to categorize individuals as either dependent or independent, consider the notion of “cognitive impairment,” an apparently straightforward and measurable term that picks out the root of many of the dependencies experienced by the frail elderly. Julian Hughes (2011), discussing a large study applying diverse metrics for “cognitive impairment” to 2640 individuals, observes that “depending on which [classification] system is being used, your chances of being declared cognitively impaired will range from one in a thousand to almost 50:50” (Hughes 2011; Stephan et al. 2007). How we understand cognitive impairment varies according to the way such impairment is conceived, and the way impairment is conceived depends not only on “the facts”, but on the underlying values that lead a researcher to design a classification

system in a particular way, and the values that lead a clinician to use one or another of the available systems. The fact is that all of us are relatively cognitively impaired, relative to some standard of evaluating the performance of cognitive tasks. Combining this with Agich's developmental understanding of autonomous agency as outlined in the previous section, we have to say more generally that every human being is profoundly dependent in ways that go to the core of our being. Rather than engaging in a simplistic attempt to categorize individuals as dependent or independent, we should conceptualize dependence as a continuum, along which each of us can be located at some point. Better still, human individuals should be seen as existing within a multi-dimensional matrix of continua, each continuum representing one sort of way we can be dependent or independent.¹⁹

For these reasons, it would be a terrible mistake, both logically and ethically, to categorize human beings into two groups: the strong, fit, and independent on the one hand, and the frail, infirm, and dependent on the other hand. This is not to say that the contrast of independent/dependent has no value. It matters to us when we can no longer perform tasks that we consider essential to expressing our autonomous agency. We can experience deficits in these areas as threats to our very self-identity—to the continuing existence of our selves. For many practical purposes, it is important that we are able to identify when individuals' dependencies have put them in a position where they require special care and attention to promote functioning and well-being and to continue to exercise autonomy. However, using terms like "frailty" or "dependence" to separate elderly people as a whole (or even a subset of the elderly, such as those requiring long-term care) and treating them as "other" and "different" from the rest of us or from "normal" human functioning and existence can have serious harmful effects. We can resist these effects by recognizing the many ways in which dependence affects every human person and sets limits to each of our abilities to exercise autonomous agency. Our level of dependency on others is in a constant state of flux throughout our lives, depending on our individual circumstances and current environmental context. For example, unexpected life events, such as the death of a family member or an unprecedented global pandemic, can cause us to experience a temporary or prolonged state of diminished capacity. We then rely on our extended social network to provide emotional, physical, or spiritual resources to help us regain former functioning.

Therefore, the binary conceptualization of independence/dependence does not duly consider the impact that others have on our lives and the relationality of actual autonomy. Paying attention to actual autonomy in the case of frail elders helps us to see aspects of autonomy that are crucial for all of us and that would otherwise be hidden if we were to remain fixed on thinking of autonomy as independence or negative freedom. For example, the exercise of autonomy in the real world is only possible within the structures of a shared social world, and this is especially true for PWD. Megan Wright argues that persons with mild to moderate dementia are capable of autonomous decision-making if autonomy is properly conceptualized as relational by using a supported decision-making model, which involves the appointment of someone as a "supporter" who helps the person with dementia gather relevant information, reflect on the situation, and convey any healthcare decisions to others (Wright 2019). Likewise, even in possession of unarguably adequate cognitive capacity to make decisions, all of us rely on others for varying levels of support when making autonomous decisions. In cases of medical decision-making, individuals have responsibilities to sustain the welfare of loved ones and the interests of these intimate relationships may outweigh the interests of the self.²⁰ Beyond medical environments, we seek advice and counsel from close family members and friends and professional counselors/therapists/life coaches, etc., and read about others who have faced similar situations for guidance on major life decisions. Our dependence on others for the ability to exercise autonomous agency becomes even clearer when we distinguish between decisional and executional autonomy; even when we have formulated autonomous decisions (decisional autonomy), our ability to carry them out and put them into action (executional autonomy) can usually only be done if we are able to coordinate our actions

with others, and if there are social (and often institutional) supports in place that provide the necessary context for us to bring about the results we desire (Agich 2003).

Beyond the necessity of material social support to accomplish autonomous action, relationships are foundational to our very ability to execute autonomy and our development of an individual identity. Autonomy itself, considered concretely and realistically, is dependent on the successful development of the skills that enable us to effectively formulate goals and execute intended outcomes on the basis of coherent and practically reasonable values. From a developmental perspective, the skills that are required to exercise autonomous agency are all formed via relationships with others. For example, language acquisition is a process of lengthy observation of adult caregivers, imitation, and reception of positive feedback until a child is finally able to state their needs and desires to their caregivers, which is an early attempt at executional autonomy (Tomasello 1992). In addition, the “independent self” we develop is not really independent at all as our identity is thoroughly constituted through our interactions with others. We are socialized to adopt many of the core values from the cultures and sub-cultures we belong to. On a macro, structural level, as described previously, individuals living under a capitalistic system internalize and assimilate values of self-interest, competition, consumerism, and financial success, affecting our goals, priorities, and self-image. On a micro-level, we often define ourselves according to the important roles that we occupy in relation to others, such as “friend”, “parent/grandparent”, or “partner”. Our interactions with others across multiple levels and spheres of life form the basis of our identity and self-image (Sallis et al. 2008), suggesting that the notion of an “independent self” completely free from the influence of others is simply not realistic. In conclusion, autonomy and dependence are far from being opposed—in multiple important ways, autonomy requires dependence on others for its existence and ongoing exercise, not only in frail elders but in each human being’s life. This should help us to address our mistaken (and ageist) ideas and attitudes that frail elders belong to a distinct category from the rest of us. All of us are thoroughly dependent, but some of us are more dependent than others in one way or another and at different times in life. Even among elders, there is a wide variation in levels of dependency—many elders retain their relative independence into late life (80s and 90s), so it is important to resist the stereotype that all older people are frail and dependent.

Just as an examination of actual autonomy reveals the embedded influence of social interactions in the lived experience of autonomy for all humans, identifying sources of meaning in frail elders lends insight into the more fundamental structures that give meaning to every human. The research on frail elders with dementia described previously reported that relationships were consistently described as a key source of meaning retained despite severely diminishing capacities (Byrne and MacKinlay 2012; Bryden 2018). This suggests that when a person loses the capacity to carry out and engage with tasks that extract meaning from work and productivity, they naturally gravitate to sources of meaning that remain. Even when the capacity for productive work is retained, when a career is de-centered, the focus on important relationships is enhanced. This is demonstrated in a recent study of retirees who prioritize relationships with friends and family over work-related endeavors after leaving the world of work (Halama et al. 2021).²¹ Interestingly, relationships naturally form the core of “meaningfulness” for young children as well. Therefore, we argue that relationships are the most fundamental source from which meaning is derived for all humans, as they are present before other sources of meaning are acquired and remain when other sources of meaning are lost. However, the majority of us, having developed into fully conscious, rational beings after childhood, are able to derive meaning from a plentitude of sources, including productivity, creativity, accomplishments, status, wealth, and more. Even when we are able to find meaning from other sources, these abilities themselves are often dependent on relationships.

As discussed above, experiencing meaning in an advanced capitalistic society is associated with achievements of various kinds, in the hopes of earning external validation of wealth, status, and accolades. However, without relationships of various kinds and

a rich social life with its various structures, most of us would not be able to accomplish much. As one example, consider the years we invest in training and education to prepare us to be able to carry out the tasks relevant to our chosen lines of work. Without teachers, mentors, benefactors, and encouragers, we would not be able to learn the skills and obtain the opportunities necessary to achieve our professional goals. In addition, to be productive and accomplished, we rely on an existing economic and technological system that has been established by other workers. In the highly technological era we live in, virtually all professional tasks rely on various technologies to be carried out, yet most of us have not even a remote idea of how to generate these technologies or how to fix them when they malfunction. We simply could not fulfill the demands of the workforce today if we were only to rely on ourselves. Beyond the practical support we gain from leveraging the work of others before us and our extended social network, social support is also essential to enriching our emotional health, ensuring we are mentally stable enough to carry out important life goals. For example, burnout is a growing phenomenon in our highly work-focused and competitive society that has been shown to have a significant detrimental effect on organizational and personal productivity. Studies of burnout have also identified that contributing factors in work-related burnout include unfair treatment at work, unmanageable workloads, and poor communication, and the main remedy to prevent and reverse burnout is repairing the relationship between management and lower-level employees.²² Here too, relationships can be seen as more fundamental than work itself since our abilities to do our work and produce depend on relationships in various ways. This point is true not only in the lives of frail elders, but for all of us, even if we see the point more clearly when we attend to the phenomena of meaningfulness in the case of frail elders.

One takeaway from all this is the importance of investing in meaningful relationships at all stages of life, as our relationships with others are fundamental both to our experience of autonomy and our ability to derive meaning in life. These lessons about the centrality of relationships to human autonomous agency and meaningfulness in life are particularly relevant in a culture in which people are increasingly isolated. Sherry Turkle in her 2011 book, *Alone Together: Why We Expect More From Technology and Less From Each Other*, argues that despite the fact that technologies have made us more connected to each other than ever before, they also have the impact of diminishing the quality of our relationships with each other (Turkle 2011). If relationships really are core to nurturing and exercising our autonomy and to finding meaning in life, we should arguably be investing much more into our relationships than we tend to do in the contemporary world. Turkle asserts that hyper-connectivity actually dilutes our attention and takes away from our ability to pour into the relationships that matter to us:

They [young people] crave things as simple as telephone calls made, as one eighteen-year-old puts it, “sitting down and giving each other full attention”. Today’s young people have a special vulnerability: although always connected, they feel deprived of attention. (Turkle 2011)

We immerse ourselves in our work and distract ourselves with pursuing our “interests” while maintaining frequent, but often shallow interactions with others through various forms of communication technology. However, if our conclusions are correct, this isolated engagement in “purposeful activity” and “independence” while neglecting to invest purposeful time and attention into our most valuable relationships might dramatically undermine our own autonomous agency and sense of meaning. This is one of the many lessons we can learn from the experience of frail elders that can help us live better, more full lives today.

4. Direction for Further Research

In this paper, we have brought together some representative conceptual and empirical work on autonomy and meaning-making in order to counter ageist assumptions about the possibilities of autonomous agency and meaningfulness in frail and dependent elders.

The terms “autonomy” and “meaningfulness” are both massively ambiguous, and many scholarly tomes have been dedicated to explicating their various senses. We consider our paper to be a preliminary foray into a much-needed interdisciplinary study of the ways in which autonomous agency and meaningfulness manifest in the midst of frailty and dependence, and, correspondingly, how these can best be nurtured in the context of long-term care, for instance. A more comprehensive investigation of philosophical and social-scientific models of personal autonomy and meaning-making will be needed in order to reduce unclarity and set our conclusions on firmer conceptual ground. Specifically, further empirical research could investigate the following questions: how do personal autonomy and meaning-making materialize in the lived experiences of those with diminished capacity? How do PWD or frail elders in long-term care exercise actual autonomy or meaning-making? What are the roles of spirituality and/or religion and mental health on an individual’s experience of autonomy and meaningfulness? More theoretically informed investigation into the experience of autonomy and meaningfulness in frail elders will help strengthen the empirical basis of the findings we have presented here.

Over the next five years, with support from the Social Sciences and Humanities Research Council of Canada, the authors will be engaged in a project that brings together philosophical/conceptual analyses with the results of related, novel sociological studies in order to better inform approaches to caring for elders living with frailty and dependence, and in particular for persons living with dementia. The future research project aims to conduct an in-depth examination of the most adequate theoretical conceptions of autonomy and meaning-making to help establish a well-informed foundation for further empirical research. By integrating this conceptual work with interviews on the lived experience of autonomy and meaningfulness with informal caregivers of PWD and, where possible, with PWD themselves, we aim to enrich the philosophical discourse on autonomy and meaning-making. Implications of this research include gaining insights on ways to improve autonomy-supportive healthcare for PWD and enhancing support for long-term care and hospice palliative care organizations to better serve frail elders and enrich the experience of meaningfulness for those with diminished capacity.

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Notes

- ¹ Two primary models of frailty were identified in the literature. A phenotype for frailty was proposed by Fried et al. as the demonstration of three of five phenotypic criteria: low grip strength, low energy, slowed waking speed, low physical activity, and/or unintentional weight loss (Fried et al. 2001). Alternatively, frailty has been operationalized as a risk index that takes into account the number of physical, cognitive, and social deficits accumulated over time (Xue 2011; Mitnitski et al. 2001).
- ² The discussion in this section draws substantially from Agich’s excellent and very thorough (2003) study, *Dependence and Autonomy in Old Age: An Ethical Framework for Long-Term Care* (Agich 2003).
- ³ Agich writes, “The problem is not with self-reliance as such, but rather that self-reliance defines individual worth. Lacking the ability to be self-reliant contributes to the feelings of worthlessness experienced by many old people. If identity and value are grounded in one’s ability to be self-supporting, then physical infirmity and disability can compromise one’s sense of personal worth precisely by compromising self-reliance” (Katz et al. 1983; Agich 2003).
- ⁴ The claims made about long-term care in this paper, as in Agich, are meant to apply to such care whether provided in an institutional setting (long-term care home or “nursing home”), in the individual’s own residence (home care), or in an alternative setting such as the home of a child or other relative or friend. Individuals in need of long-term care generally require assistance

with activities of daily living (shopping, cooking, cleaning, feeding, bathing, toileting, etc.) in addition to medical attention (Agich 2003).

“The most striking feature of long-term care is that adult individuals suffering from diseases and illnesses of being old experience a compromised vigor and ability to function that requires regular care [E]lders in long-term care often deviate in obvious ways from the ideal of the competent, rational, and free decision maker that is implicit in the commonplace understanding of autonomy” (Agich 2003).

One should consider, in this context, Kitwood’s (1997) account of the role of malignant social psychology in undermining personhood in individuals with dementia (Kitwood 1997). Goffman’s (1961) notion of the “total institution” is another highly relevant sociological construct, particularly in relation to the effects of institutional factors on self-identity and autonomy (Goffman 1961).

Although we have chosen to focus on Agich’s general account of autonomy in dependent elders, similar approaches—but with a more specific focus on persons with dementia—can be found in the work of Kitwood (1997), Brooker (2019), Hughes (2011, 2014) and others.

“Identification . . . is logically prior to freedom; autonomy is best understood on the basis of the possession of an identity or of a self having a particular determinate nature and character” (Agich 2003). As such, identification “precedes autonomy as independence” (Agich 2003).

It is beyond the scope of this paper to characterize Agich’s particular theory of the self in relation to other models available in the relevant literature. Suffice it to say that, in contrast to split-level models like Frankfurt’s or Dworkin’s, Agich, following Friedman (1986), conceives of the self as “an empirical product” built up “from experience, from one’s actual choices and motivations”, and “amenable to expression in terms of higher-level principles. This sense of self then serves as a normative principle for identification of subsequent experiences, choices, and so forth” (Agich 2003).

Agich notes, “Without social life and intact processes of socialization, the emergence of an intact individual as a biopsychosocial unity capable of thought and action would be impossible. Indeed, social life makes autonomy, no matter how we define it, possible, because without the social world there would be no space for agency. Human action acquires its meaning in and through the social world” (Agich 2003).

“Affections determine who we are . . . Formation of the rational will from primitive desires or preferences occurs only in relationship with others, relations that are made possible through bonds of affection” (Agich 2003).

If this sort of offense to autonomy seems trivial, consider instead the choice many elders must make between imposing intense burdens on their family members or moving into a nursing unit in a long-term care home. Depending on their circumstances and means (financial, relational, etc.) this may pose a tragic choice for many elders who find themselves profoundly unable to identify with either of the options and yet are forced to choose between them.

Other environmental or structural factors that inhibit autonomy include the low pay and high turnover rates of long-term care home staff which, combined with the transience of residents themselves, contributes to an “air of change, unreality and rootlessness” that “creates stress and confusion for the residents”, exacerbating the effects of cognitive and physical impairments (Agich 2003). Restraining an elder who exhibits “problem-behaviour” such as wandering, without attempting to understand the meaning of the behavior for the elder, is another characteristic way in which we undermine, rather than promote or enhance, autonomous agency.

Another angle from which to appreciate the autonomy that remains in the context of frailty and dependence involves distinguishing between *decisional autonomy*, which has to do with internal processes of decision-making, and *executorial autonomy*, which concerns the ability and freedom to bring about what one has decided in the external world. As Agich puts it, “because decisional autonomy can remain intact when executorial autonomy wanes, failure to provide adequate help to an incapacitated elder can seriously efface autonomous choice” (Collopy 1988; Agich 2003). Even though an elder cannot bring about the effects of their decisions unaided, they can do so with the help of others so long as those others do the necessary work of understanding the decisions themselves.

Global meaning refers to the systems that orient a person’s views on the world, including their fundamental beliefs, values, goals, and expectations (Park and Folkman 1997). Constructed in early life and modified by personal experiences, global meaning influences a person’s thoughts, actions, and responses to situations (Park 2010). Situational meaning is the meaning assigned to a particular event (Park 2010). When challenged with stressful events such as serious illness, individuals appraise the situation and assign situational meaning. If the appraised meaning conflicts with their global meaning, the individuals will experience distress to the level of discrepancy.

See Park and Folkman’s theory of global and situational meaning (Park and Folkman 1997).

See Park and Folkman’s discussion of “meanings-made” for more information (Park and Folkman 1997).

Spiritual reminiscence is “a way of telling a life story with an emphasis on what gives meaning to life” by reflecting on important experiences that have brought joy, sadness, anger, or regret. This functions to better examine the emotional impact of life events and move towards a discussion of the deeply felt meaning associated with life experiences as opposed to the rote recapitulation of events (MacKinlay and Trevitt 2010).

The idea here is that each functional capacity (e.g., ability to remember names or to recognize people, ability to feed or bathe oneself) can be understood as a continuum between two poles. On one end would be “utter incapacity/inability to perform the

function in question,” whereas the other (idealized) pole would be “perfect capacity to perform the function without assistance.” Putting together all the functions that matter to us would yield a complex matrix of continua of this sort, and each individual would find themselves somewhere between the two poles for each of the relevant functions. The result of locating any given individual within this matrix would give a concrete and detailed picture of that individual’s level of dependence/independence.

- 20 Ho (2008) uses a case study of a man suffering from severe vasculitis with a poor prognosis who reversed his refusal of life-saving measures after discussion with his wife to suggest that a consideration of family interests does not necessarily constitute “undue pressure” (Ho 2008). The model of autonomy embraced by Western bioethics that considers individuals as completely separated from others by boundaries that can only be justifiably breached by the explicit and voluntary consent of self-determining subjects is misguided. Rather, the self is highly relational and we cannot make decisions wholly apart from the influence of others.
- 21 This study represents a qualitative inquiry into how Slovak retirees reconstruct meanings during the transition to retirement. Forty new retirees were interviewed and data were analyzed, showing that once retired, the participants generally continued to rely on previous meaning sources such as work and family. Family remained a primary source of meaning for 70% of participants before and after retirement, whereas 15% fewer participants identified work as a source of meaning after retirement (Halama et al. 2021).
- 22 According to the WHO, “Burnout is a syndrome conceptualized as resulting from chronic workplace stress that has not been successfully managed” (Burn-Out 2019). A central cause of burnout is a lack of belief in the significance of work-related pursuits. Although certainly some work pursuits are fulfilling for individuals, the high prevalence of burnout, particularly in demanding, altruistic occupations suggests work achievement itself is not inherently meaningful. However, recent discourse suggests burnout is not solely job-related; disillusionment within any of our roles, even as parents, spouses, and children, can cause burnout. This suggests that focusing on the quality of our relationships with others can counter some of the negative effects of burnout. The importance of relationship quality over the quantity of interactions is further described by Sherry Turkle.

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