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Abstract

The interdisciplinary field of bioethics focuses on what it means to be a person, flourish as a person and be respected as a person in different conditions of health, illness, or disability. Bioethics and policy research considers normative questions such as how a good society, through its priorities and investments, should demonstrate its commitments to the lives of different populations. Bioethics and humanities scholarship, often known as “health humanities,” shares affinities with age studies and disability studies, and with narrative-based approaches to the study of human experience. Gerontology is concerned with the many aspects of life that affect how people age, including social structures and values that influence the experience of growing old. In this paper, we briefly explore the evolution of bioethics, from a discourse that emerged in relation to developments in biomedicine, bioscience, and biotechnology; to research ethics; to broader ethical questions emerging from real-world conditions, with attention to how bioethics has considered the experience of aging. Until recently, most age-focused work in bioethics has concerned age-associated illness, particularly end-of-life decision-making. Given the reality of population aging and the ethical concerns accompanying the shift in age for most places in the world, the further evolution of bioethics involves greater attention to the support of flourishing in late life and to social justice and health equity in aging societies. We argue that the discourses of bioethics and critical gerontology, in dialogue, can bring new understanding of privilege and preference, disparity and disadvantage, and reflection and respect for aging individuals.

Keywords: Bioethics, Health humanities, Population aging, Social justice

Introduction

In this essay, we reflect on a developing and deepening practice of two interdisciplinary fields— bioethics and gerontology— that in recent years have been “thinking together” about what it means to be an aging person and about the consequences and opportunities of population aging. We make an argument for even greater collaboration between researchers, practitioners, and educators in bioethics and in gerontology as a consequence of the Covid-19 pandemic and the multiple inequities it has revealed. Bioethics, in its broadest definition, focuses on what it means to be a person, to flourish as a person, and to be respected as a person. As an interdisciplinary field of scholarship drawing from philosophy, medicine, nursing, law, public health, literature, history, and the social sciences, among other disciplines, bioethics and the related discourse of health humanities focuses on personal and societal expressions of values or questions about what it means to live in relation to health, illness, suffering, disability, life stages, care, medical treatment, and biotechnologies; and to be afforded or denied opportunities to flourish in the context of cultures, societies, and environments. Such questions are often called “normative” or “ethical” questions. They are frequently phrased in terms of “should,” “ought,” or “the right thing to do,” suggesting the relational nature and applied contexts of these questions. As an interdisciplinary field of scholarship drawing from the social sciences, public health, social work, philosophy, and history, among other disciplines, gerontology is concerned with myriad aspects of later life, including the personal and societal structures that affect how individuals and groups experience old age. When gerontologists based in public health research, for example, seek to understand how social policy *should* recognize and support the experience of aging, we are asking a set of ethical questions: How should a good society demonstrate, through its priorities and investments, that it values older adults as members of society? How should a good society recognize human interdependence and care needs, including in

late life? When public health frames late life in terms of “healthy aging,” what persons, populations, and aspects of late life are excluded, and what are the consequences of exclusion?

We begin with a brief overview of bioethics, followed by a discussion of what gerontology brings to bioethics, with examples from recent collaborations to support mutual learning and establish practices of working together. We then explore examples of applied bioethics in the context of current values-laden questions related to aging, such as the just and equitable treatment of older persons in research; access to medical interventions, and concerning self-determination (or autonomy) in medical decision-making, with close attention to how work in these domains can be expanded to more fully account for experiences of aging beyond medical and clinical research contexts. Finally, we suggest ways that a practice of thinking together across the overlapping conceptual discourses of bioethics and humanities, humanistic gerontology (which includes interdisciplinary humanities and interpretive social sciences; Cole, Ray & Kastenbaum, 2010), and critical gerontology (which challenges epistemological functions and social influences shaping gerontology; Holstein & Minker, 2007; Minkler, 1996) supports the development, process, and translation of empirical research and the identification and analysis of conceptual problems related to values and later life.

What is bioethics?

Bioethics took shape in the late 1960s in relation to developments in biomedicine, bioscience, and biotechnology, such as organ transplantation, genetics, and hemodialysis (Callahan, 1973; Jonsen et al., 1993). By the late 1980s, bioethics began to include issues related to aging (Cole, Ray & Kastenbaum, 2010). Over decades, an interdisciplinary mode of inquiry created by moral and political philosophers, theologians, physicians, scientists, and legal scholars became socialized around the goals of biomedicine. Consequently, bioethics scholarship, empirical research, and

education is often located in faculties of medicine. (The Hastings Center, an independent research institution based in the US, and The Nuffield Council on Bioethics, an independent research institution based in the UK, are important exceptions.) Bioethics practice often takes place within academic medical centers and as part of biomedical, bioscientific, or biotechnological research.

For example, health care ethics is an applied branch of bioethics that has developed a methodological approach (clinical ethics consultation) to managing ethical uncertainty in health care work, often arising in the care of older adults with progressive or terminal conditions (Berlinger et al., 2021). Hospitals are required, as a condition of accreditation, to have some mechanism for addressing ethical challenges arising in patient care. Physicians and nurses may request a clinical ethics consultation when there is uncertainty about how to make decisions concerning medical treatment when a hospitalized person lacks the cognitive capacity to make this decision. The typical hospitalized person is experiencing an acute episode of an age-associated condition; bioethics practice in this setting often concerns persons in late life.

Research ethics is another applied branch of bioethics, likely to be familiar to gerontology researchers through the process of seeking study approval by an Institutional Review Board (IRB). Protocols for studies involving human subjects reflect ethical standards developed through deliberative processes concerning informed consent, privacy, safety, data protection, and other aspects of research conduct. The Belmont Report, published in 1976, is an example of early, still influential interdisciplinary work to draft and develop consensus around principles to guide research conduct (OHRP). Some bioethics researchers study the processes and consequences of evolving areas of research, particularly in genomics. The National Human Genome Research Institute (NHGRI) is distinctive among National Institutes of Health (NIH) agencies in having a funding stream dedicated to “ethical, legal, and social implications” (ELSI) of genetic and genomic research. NIH also has a Department of Bioethics that provides consultation to the NIH Clinical Center and produces scholarly publications on a range of topics. In many NIH agencies, attention to bioethics focuses on

the ethical dimensions of research conduct. A relatively new funding mechanism (Administrative Supplement for Research on Bioethical Issues) enables funded investigators to secure an additional grant to explore ethical questions arising from real-world study conditions.

The ethical dilemmas and challenges of clinical work, human subjects research, and emerging genomics research, while significant, are narrower and more technical than the big questions of ethics in moral philosophy and political philosophy. These questions include: How should I be as a person? How should I act in relation to others? What does it mean to live a good life under different conditions and stages of life? How should a person's capacity to live a good life be supported by the society in which they live? What do we owe to persons beyond our own families? What concept of social justice equitably reflects the interests of currently old and currently young generations? What do persons alive now owe to future persons, to other species, to the environment? What's the right thing to do in response to suffering, inequality, or injustice? From a bioethics perspective, these are difficult and necessary questions relevant to all levels of human experience, and should not be dismissed or minimized as "abstract" or "ivory tower" questions. In recent years, there have been calls within bioethics to look beyond "the clinic" and "the lab," where the field had been socialized, to engage or reengage with these moral and ethical questions in broader social contexts, as they affect human health and wellbeing and other aspects of human experience.

Until recently, bioethical questions in the context of population aging have tended to be framed in terms of health care for older adults, reflecting the socialization of bioethics around health care ethics and clinical ethics consultation in the care of hospitalized patients (Cole, Ray & Kastenbaum, 2010.) Bioethics guidance concerning older adults has focused on medical decision-making and advance care planning aimed at respecting patient self-determination; relieving suffering through access to palliative and hospice care, and supporting surrogate decision-makers and family caregivers (McCullough, 2000). This type of guidance imagines and aims to respond to

ethical uncertainty in how to make decisions concerning treatment and care concerning a person nearing the end of life due to age-associated chronic progressive illness and comorbidities, the major causes of death in aging societies. (Covid-19 mortality is also strongly age-associated, and similar questions have arisen under pandemic conditions.) A major shortcoming of this type of guidance is that it has little to say about aging itself, or concerning the life of an older adult who is not a patient or a prospective patient, or concerning the range of social policies that shape the experience of health in late life.

To remedy this narrow focus, The Hastings Center launched a two-year, grant-funded planning project in 2016, to look anew at big ethical questions as they were arising in the context of population aging, and to consider what makes a good life in late life. This institution was well-placed within the field of bioethics to take on this exploratory work in part because of its decades-long leadership in developing guidance on treatment decision-making and care near the end of life, often in the context of age-associated progressive conditions (Wolf et al., 2015). Following a comprehensive updating and expansion of this work that was published in 2013, researchers at this institution sought to look at ethically significant dimensions of late life occurring before the “end of life”; that were not shaped by treatment decision-making, and that involved social experiences and structures beyond health care. We address some of the key findings of this project in the next section of this paper.

Learning to think like gerontologists (2016-18)

At the start of the 2016-18 planning project, it became clear that ethical questions related to aging and later life included considerations such as the cumulative effects of unequal life course events on health, finances, cognition and other aspects of aging; issues of access and equity concerning needed services; age in the context of care; precarity of housing and living arrangements; flourishing

and social death, and other topics that largely sat outside the interdisciplinary bioethics literature. Bioethics work on care near the end of life, by scholars such as political philosopher Bruce Jennings, had been informed by the conceptual and empirical work of distinguished age-focused researchers such as sociologist Carroll Estes, public health and health policy scholar Ruth Finkelstein, medical anthropologist Sharon Kaufman, geriatrician Joanne Lynn, and philosopher Harry (Rick) Moody, among others. Intersecting scholarship between bioethics and feminist philosophies of care (sometimes known as “care ethics” or “care theory”) frequently concerned topics such as intergenerational family caregiving, with Jennings, Eva Feder Kittay, Carol Levine, and Hilde Lindenmann (Nelson) as notable scholars. However, the professional networks of bioethics scholars and of age-focused scholars tended not to overlap. There were few bioethics scholars at gerontology conferences, and few gerontology scholars at bioethics conferences.

To remedy this situation, project leaders sought out consultations with research gerontologists in the US and other aging societies, and recruited social and environmental gerontologists, plus age-focused researchers from fields such as economics, community planning, and urban planning, for the project’s work group. (One early project learning was that not all age-focused researchers self-identify with gerontology. Scholars of aging and housing, for example, may network more frequently with planning and design research communities, reflecting their training, orientation, and audiences.) As an essay in the peer-reviewed volume produced by this project noted, one aim of this planning project as it evolved was to help bioethicists learn how to think like gerontologists: “to consider the cultural and societal values—past and present—that shape the experience of aging, to recognize people as complex beings whose individual lives do not follow predictable patterns or easily identified trajectories, and to recognize our own habits of regarding older persons as ‘other’ and the consequences of ‘othering’ for older persons and social systems” (de Medeiros, 2018, p. S10). Bioethicists accustomed to thinking about aging in terms of age-associated illness were introduced to the life course perspective; the limits of using chronological

age to understanding aging; the ways in which women are prematurely “aged” due to gender biases, and the importance of language in shaping cultural narratives and correcting stigma.

The Introduction to the peer-reviewed volume published in 2018 noted that this call for more sustained attention within bioethics to the experience of aging was part of a needed alignment of the field “toward social justice and problems of injustice” (Berlinger & Solomon, 2018, p. S4). Through this critical move, bioethics was called to “widen its lens from the clinic to the community, engage with demographic change, and contribute to policy solutions capable of improving the experience of aging and the lives of people in aging societies” (Berlinger & Solomon, 2018, p. S4).

Further research collaborations (2019-2022)

Several collaborative projects and areas of inquiry developed from the initial planning initiative to bring gerontologists and other age-focused researchers into sustained discussion and collaboration with bioethics researchers. One ongoing area of collaborative inquiry focuses on housing as a site of health, flourishing, or precarity for older adults. Housing in late life is strongly shaped by socio-economic factors; most older adults live on fixed incomes that limit their housing options as their housing needs change. The willingness of communities, through mechanisms such as zoning and planning, to prioritize housing affordability and accessibility for older adults determines whether a community in which a person hopes to “age in place” will equitably accommodate aging and caregiving, or will perceive housing as a problem for individuals and their families to solve on their own. A one-year translational grant from the funder of the initial planning work supported additional publications and events in 2019, including a livestreamed public symposium on “planning, design, and spatial justice in aging societies” (*Aging in [a] place*, 2019). Presenters at the public symposium, which was hosted by a leading school of design, explored housing and community inclusion challenges facing older adults, with perspectives from researchers in community planning,

environmental gerontology, public health policy, urban planning, and other fields. This event also used tools developed by the Just City Lab, which studies the role of planning and design in mitigating structural injustice, to help participants reflect on community-level values that can support (or hinder) the experience of aging in different places. (Just City Lab, n.d.) The public symposium coincided with a participating organization's quantitative report on "unequal aging," documenting trends toward greater socio-economic inequality among older adults. These trends intersect with the racial "wealth gap" produced by historical and continuing residential segregation that has blocked Black Americans from building and transferring wealth through home ownership (Joint Center for Housing Studies of Harvard University, 2019a, p. 19-20). These data inform a current (2021-2022) research study described later in this paper.

The other major area of ongoing research collaboration between bioethics and gerontology that has developed out of the 2016-2018 planning project focuses on dementia. Current collaborative research on living alone with dementia (Girling & Doyle, 2020) has included a deeper analysis of informed decision-making as it arises in the context of cognitive impairment and participants' housing and social environments. This research collaboration holds promise to correct problems of underrepresentation of persons with dementia and of community-based settings in data on aging, by helping clinically-focused research gatekeepers, such as IRB members, to better understand capacity to consent in community-based research. Other ongoing research collaborations and projects in development aim to bridge the conceptual gap between gerontological research on the experience of living with dementia and bioethical perspectives that have tended to frame dementia in terms of treatment decision-making capacity. While loss of capacity associated with dementia is significant when a medical decision needs to be made, it is insufficient as a way to understand factors that shape everyday life in home and community settings and to support the experience of living with dementia.

The critique of ageist and ableist language and images and the practice of reframing problematic or outdated language is well-established in gerontology publishing and other communications (Journal of the American Geriatrics Society, n.d.). A bioethicist would recognize this work as an ethical standard that is part of the professional role of doing gerontology. Applying this work from gerontology to bioethics publishing and communications is a further product of ongoing collaboration between interdisciplinary fields, overlapping with similar discourse critique and practical solutions grounded in disability studies (Centre for Ageing Better, 2021; The Art of Flourishing: Conversations on Disability, 2020-21).

Another important area of collaborative thinking, relevant across research collaborations, concerns the powerful framing effect of Medicare on the study of aging. Because nearly all older adults qualify for Medicare at age 65, Medicare (CMS) data are immensely important in understanding how older adults use health care services (Mues et al., 2017). Pilot studies to expand or improve health-related services for older adults or associated with aging often aim to make an evidence-based case for Medicare financing. Given these conditions, it is easy to conflate “Medicare” with “aging” and “aging” with “health care utilization.” Collaboration with researchers who study aging outside of health care contexts helps bioethicists and health policy scholars to develop a more nuanced understanding of large datasets relevant to aging research. For example, housing researchers use US Census Bureau data to identify neighborhoods with high concentrations of “cost-burdened” older-adult households (Joint Center for Housing Studies of Harvard University, 2019b, p. 8-9).

Bioethics is also enriched by knowledge of research methods grounded in social gerontology and environmental gerontology, applied to residential and community settings, or concerning contexts shaped by Medicare exclusion (Greenfield et al., 2019). Most research questions related to housing and many questions related to dementia, where most care is provided outside of clinical settings, fall into these categories.

Collaboration with gerontologists reminds bioethicists of what they should already know: that it is essential to look beyond the clinic and clinical data to understand human experiences and what shapes these experiences. Scholars and researchers based in medical schools and clinical contexts are familiar with questions that privilege issues that arise in clinics and in the lives of older adults enrolled in clinical research studies. Developing the habit of learning and explaining what aging looks like from the perspective of an age-focused field helps bioethicists remember, and remind current and future clinicians, that “the community” is the typical place where aging occurs.

Working together: critical areas of collaboration for post-pandemic research

The Covid-19 pandemic has accelerated conversations between empirical researchers focused on identifying social drivers of health disparities and scholars focused on how societies should change by intervening in problems of structural inequality that undermine the health and wellbeing of vulnerable populations. In the context of age-focused empirical research, collaboration between bioethics and gerontology in study design, implementation, and translation of research may ensure attention to normative questions concerning societal support for the experience of late life. The involvement of scholars with expertise in different types of health and social policy related to aging can strengthen study design and analysis of findings by identifying realistic routes to policy solutions (Krieger et al., 2021).

Critical discussion informed by expertise in research ethics can help to identify ways to engage with research ethics systems about how best to support gerontology researchers whose work contributes to equity in representation concerning participants with dementia and concerning community settings, and also to larger questions of how to understand and mitigate vulnerability. In the research context, the label of “vulnerable population,” referring to members of groups in need of greater protection from risks associated with research participation, is often applied to older

adults, especially those with cognitive impairment or dementia. In population health, “vulnerable populations” refers to groups in society who experience health inequities due to underlying inequalities in that society, and also to groups who are vulnerable to health harms due to personal medical factors, which may include age or age-associated conditions. For example, adults age 75 and older have been a vulnerable population in the Covid-19 pandemic because of their high risk of developing life-threatening Covid-19 if infected and also because they are vulnerable to the consequences of inequalities in how societies value and treat people in late life (Flood et al., 2020, p. 5-19).

Global pandemic and outcry against racial injustice have sparked discussions about how research on pandemic experiences and outcomes can support progress on mitigating social vulnerabilities and promoting social justice, including justice in access to experiences of health and wellbeing (health justice or health equity). Critical areas of research on older adults going forward that benefit from collaboration between gerontology and bioethics include dementia and caregiving; housing and community; and “big data” problems of underrepresentation and bias.

Dementia and caregiving: The highest Covid-19 mortality rates occur in people ages 85 and older, followed by people ages 75-84. Long-term care facilities have been frequent sites of outbreaks among residents and staff, accounting for most deaths in some states and nations. The vulnerabilities of people in need of care – including but not limited to people with moderate to advanced dementia – and of people who work in the low-wage care workforce are linked. Going forward, gerontology and bioethics can develop behavioral and social science research on the pandemic experiences of people with dementia, family caregivers, and paid care workers in long-term care and home health settings, informed by normative work on care (Gary & Berlinger, 2020). Data and analysis on these experiences can inform a range of public health policies and reforms, including financing for dementia care outside of congregate settings, better supports for family caregivers; improved wages, benefits, protections, and training for aides, and safer and more

humane congregate care settings. Research on nascent dementia-friendly networks serving people with early to moderate dementia is also needed, to understand how this approach to supporting the social lives of people with dementia, and of caregivers, can support good lives in community and serve people in diverse socioeconomic communities.

Housing and community: The Covid pandemic has stress-tested this nation's housing, which already poorly serves low and middle-income older adults due to community-level stigma associated with the planning and building of affordable, accessible, congregate, or multi-unit housing. The need to physically distance and limit person-to-person contacts has also revealed the immense importance of a person's housing, community, and social networks as sites of health and wellbeing. Current research collaborations that include gerontology, bioethics, public health, and housing studies are beginning to analyze how services improvised during "lockdown" to ensure the basic needs of older adults and to compensate for restrictions on social experiences may help make progress on these underlying inequities. As we learn more about how older adults adapted to physical distancing – by building social networks among neighbors or learning how to use Zoom to continue to participate in meaningful activities – we may learn how to imagine, create, and sustain communities that are more supportive of the lives of older adults and of human interdependence.

"Big data" and older adults: Bioethicists' growing expertise in the ethics of "big data" (i.e., large datasets) can strengthen gerontology research. One major ethical concern is how algorithms used in resource allocation handle data that reflecting underlying social inequalities, such as poorer health outcomes associated with race, ethnicity, or wealth. If machines "learn" to reproduce inequality from these data, resource allocation by algorithm will be unjust. The underrepresentation of populations – such as community-dwelling older adults – from research datasets is another ethical concern. When research data reflect populations seen in clinical settings, these data may overrepresent medical experiences and fail to capture aspects of aging that are not mediated or measured clinically. Collaboration with bioethicists with expertise in bioinformatics can help

gerontologists who conduct or interpret quantitative research to analyze problems of inequality reflected in datasets that include older adults. These collaborations may also provide a vector to medical education and clinical research training, to help clinically-focused practitioners and investigators to connect with gerontology research and better understand experiences of aging outside the clinic. A history of emphasis on informed consent as a needed corrective to histories of medical paternalism and research misconduct means that bioethics literature frequently invokes self-determination as a value, principle, or right. The emerging post-pandemic bioethics, shaped by knowledge of health disparities revealed anew by Covid-19 data, may see greater emphasis on population-level analysis and on the individual in relation to structural sources of harm (Wynne et al., 2020).

Conclusion: The value of thinking critically, together

Contemporary gerontology encompasses a healthy practice of critical gerontology as a reflective mode for empirical and mixed-method research, as seen in the “precarity” critique of the influential concept of “healthy aging” (Grenier & Phillipson, 2018; Grenier, Phillipson & Settersten, 2021). Like the practice of correcting ageist and ableist language and framing better ways to communicate about aging and disability, the critique of one’s own discourse and priorities is a useful model for the younger discipline of bioethics. Evolving discussions among philosophers and other humanities scholars in the overlapping disciplines of bioethics, care ethics, and justice theory are engaging with concepts from critical gerontology to consider how to develop an influential theory of social justice – the capability (or capabilities) approach of economist Amartya Sen and philosopher Martha Nussbaum – to better account for people who may be excluded from “health”-focused accounts of capabilities because of their health status or care needs (Venkatapuram, 2011; Dunn 2018, Miller 2020). More broadly, a practice of critical bioethics, informed by critical gerontology, can reflect on the privileging of self-determination and individual preferences, mindful of disparities

borne by members of populations who are socially marginalized, economically disadvantaged, and less likely to be seen as individuals to be respected.

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