

The Rise and Role of the Oldest Old: Need for Study and Theory

Anita Yuskauskas, Ph.D., Elias Cohen, J.D., & James Conroy, Ph.D.

Abstract

This article identifies the dearth of research into the personal lives of the oldest old, the fastest growing age group in the United States. It calls for a better understanding of this unprecedented population change in order to equip aging individuals and society for the approaching population bubble. Social attitudes and the pervasive presence of disability in old age suggests parallels with Wolfensberger's Social Role Valorization schema (2000). The research raises new questions about old concepts such as the disengagement theory and offers alternative ways to understand the oldest old. Finally, it offers a compelling framework within which to focus future research.

We know little about the personal experiences of people who outlive the expected limits of human survival—otherwise known as the oldest old (Borglin, Edberg and Halberg, 2005; Sarvimaki and Stenbock Holt, 2000). The group is largely invisible in our society, according to John Leland, the journalist who wrote a quintessential series of articles in the New York Times on the group (Leland, 2019).

This article examines America's oldest old, those aged 85 and above, using a literature review and personal reflections from a prominent 92 year old, who was the first Commissioner of Aging in the State of Pennsylvania, former Editor in Chief of the *Gerontologist*, a public interest law attorney, a researcher, and an author. His reflections embody both the perspective of a professional and the experiences of a subject. His opinions generally support current literature, though in some instances he challenges prevailing thought or proposes new lines of research.

Though somewhat unconventional, the article's approach highlights an imperative for improved social understanding of the oldest old. It supports Conroy and Cohen's (2019) call for qualitative research on the oldest old, to explore "what's important, what really matters, attitudes and qualities of life" (p. 6). Their call for research has a clear purpose: to prepare the oldest old and the rest of us for the aging experience, to understand the range of options and tools at our

disposal, and to thwart devaluation of yet another segment of society, similar to the massive institutionalization of persons with disabilities in the 1960s. Segregation and isolation of people with developmental disabilities in public institutions, for example, increased exponentially until 1969, at nearly 200,000 people, when it began to decline (Larson, Eschenbacher, Anderson, Taylor, Pettingell, Hewitt, Sowers & Bourne, 2018). Though short on answers, this article raises serious and important issues facing our society, and our lack of preparedness to support the oldest old as they move through unchartered territory.

Literature Review

How are we to understand social participation and valued roles for the oldest old? The ends toward which this group is focused may not be the same as those of their younger counterparts. As the fastest growing cohort of Americans enter the oldest old phase, our current ways of knowing and assimilating the group may be unfamiliar. We may be challenged to reevaluate how we think about the age group and the policies that benefit them. In fact, Riley and Riley (1989) suggest there is dissonance in our policies, between the potential contributions of older people and the ability of society to harness and make use of their skills. Known as *structural lag*, older people are subject to obsolete social roles nominally synchronized with the realities of their aging. This phenomenon occurs regularly, with every generation. Yet social stereotypes from one generation to another are slow to change, and laggard to grasp the dynamic and rapidly changing realities of aging. As a result, Riley & Riley (1989) assert that social roles and the aging phenomenon are not aligned and must be rediscovered with every generation. The dissonance between how society views the oldest old and how individuals in this cohort may actually perceive themselves is a subject of this study.

The number of Americans aged 85 and older is expanding rapidly. According to a Census Bureau report from 2018:

The number of people in the oldest old age group, which refers to those aged 85 and over, is projected to grow from 5.9 million in 2012 to 8.9 million in 2030. In 2050, this group is projected to reach 18 million. In 2050, those aged 85 and over are projected to account for 4.5 percent of the U.S. population, up from 2.5 percent in 2030 (Roberts, Ogunwole, Blakeslee & Rabe, 2018).

The oldest old group is the fastest growing segment of the United States' population (Roberts et al., 2018), and this trend is emerging not just in the United States but around the world (Taylor, 2014). Yet we are ill prepared as individuals and as a society to understand and engineer this phase of our humanity. Passing into the oldest part of old age, and then successfully maneuvering through it, is a relatively new and unprecedented phenomenon (Taylor, 2014).

Ageing Theory – Then and Now

Ageing theory has changed and evolved over time, reflecting our emerging understanding of the ageing experience (Lange & Grossman, 2006). To name a few, Cumming & Henry (1961) advanced the Disengagement Theory, which postulates that as people age, they gradually withdraw from society, and eventually disengage. Havighurst & Albrecht (1953), and later Havighurst (1961), put forth the Activity Theory, which counters the Disengagement Theory and

proposes that, as they age and lose younger roles, older people develop alternative roles, though activity and relationships remain important. Neugarten and her colleagues similarly challenged disengagement, emphasizing that aging and activity lead to greater satisfaction in old age (Havighurst, R.J., Neugarten, B.L., & Tobin, S.S., 1963; Neugarten, Havighurst & Tobin, 1968). The Activity Theory became and remains a popular theoretical framework in aging. Today, “the principles of Activity Theory are evident in the work of most gerontologists” (Hillier, 2015, p. 89). But does this world view comport with the perspectives of the oldest old? According to the co-author:

It’s very hard... I think there is much more to Disengagement Theory than we think. The early thinking looked on it as a destiny, that we are destined to disengage because we lose friends, they die, they move away. We lose contact with the professional world, with our colleagues. So we produce a substitute – a senior center. I don’t think that cuts it. I don’t know what the parallels are for the very old population who are limited in mobility to engage with others. It’s an elaboration of Disengagement Theory. People didn’t like Disengagement Theory because it wasn’t the logical thing to do. But we have to look at the phenomenon of disengagement” (E. Cohen, personal communication, April 6, 2019).

Though quickly usurped by the Activity Theory, and the subject to numerous critiques, “the ‘disengagement controversy’ dissipated long before the fundamental issues it raised were fully resolved” (Achenbaum & Bengtson, 1994, p. 760). But perhaps the disengagement theory raised issues that warrant further consideration in aging theory today. For instance, Carsten, Isaacowitz & Charles (1999) raised the possibility that time and emotion play an important role in the perceived disengagement of older people. Drawing on the socioemotional selectivity theory, the authors assert that older people are generally better at regulating negative emotions, and function more maturely in their cognitive comprehension of emotions. So, when limited by time, older people engage in a natural “pruning process” of social contacts. As reported by the authors, this is not the result of disengagement, but is connected to a perception of limited time. As such, individuals tend to give prominence to “emotionally close social partners and disregard more peripheral ones as time in life grows increasingly limited (1999)”.

This research provides an alternative to the disengagement theory. It offers insight into the changing perceptual realities of older people, which leads to a change in their social behavior. Thus, different conclusions may be drawn about the diminishing social lives of older people. As people age and we learn more about their experiences, we are challenged to better understand the correlation between theory and experience, and align current suppositions with the realities experienced by the oldest old.

Isolation and Loneliness

Research into loneliness offers additional insights into disengagement and the behaviors of older people. Cacioppo, Capitanio & Cacioppo (2014) discuss the distinction between isolation and loneliness - social isolation is physical separation, while loneliness is feelings of separateness. Loneliness is “a subjective, unpleasant experience that occurs when the desired level of meaningful social contact is less than what is available” (Allen, 2018). It causes a set of social and biological responses that trigger serious physical problems. In their Evolutionary Theory of Loneliness, Cacioppo & Cacioppo (2018) hypothesize that a strong behavioral and biological association exists between loneliness and premature death at all ages. While not all who are isolated are lonely, isolation is a critical risk factor for loneliness. At the same time, growing

numbers of our oldest old citizens will likely experience isolation at some time in their lives. Understanding the biology of loneliness and its impact on our most vulnerable is critical, according to a study by the National Institute on Aging (2019), which is looking at early social interventions to address the physical correlates of loneliness, which may include inflammation, chronic diseases, and cancer.

The co-author explains:

The energy required for social engagement diminishes [with age] but does not disappear entirely. Substitutes for the former stimuli are blocked by deaths of friends, colleagues, and associates, geographical relocation, losses of ‘membership’ in earlier groups, and absence of ‘job’ and job-substitute connections. Adult children move away or reduce contact. The remarkable connectivity provided in the digital era does not yet seem to remedy the void in social engagement that seems the norm for old age, even as we move further into the twenty-first century. (E. Cohen, personal communication, October 25, 2017).

In fact, the digital era offers a mixed bag when it comes to social engagement. It has resulted in less human contact in some instances, as in the widespread use of ATMs, self-scan grocery check-outs, and on-line psychological therapy (Allen 2018). Yet digital technologies also enable unprecedented communication capabilities. By shrinking space and time, they promote family connections and even enable caregiving across the miles. At the same time, disparities have become more pronounced in the age of digital technologies due to a lack of access and technological literacy (Byrum, 2015). Given the exponential speed of change, no population is more impacted by technology than our oldest citizens (Vaportzis, Clausen, & Gow (2017).

Age Related Disabilities and Healthcare Policies

With the impending and rapid social expanse of the oldest old, “development of mortality, disease, and disability rates in elderly people will have a fundamental effect on sustainability of modern society” (Christensen et. al, 2009, p. 1120). In fact, Christensen and his colleagues add a fourth age to the major life phases, which include childhood, adulthood, old age and now, the oldest old life phase. The expanded framework elucidates population change and the impending need for social and economic policy accommodation in areas such as healthcare benefits, social programs, retirement age, and employment. As the oldest old expand in numbers, society is likely to experience unparalleled transformation.

I think there is something here to talk about---implications of a restructured society, changed patterns of dependency and support, new ways of assessing gender relevance in the labor force, retirement patterns, changes in childbearing patterns... All of these simultaneous changes in population makeup, gender roles, and retirement are relevant to how we think about old age, old people; what they *do* and what they may require, and how and who pays for it. It is much in flux. (E.Cohen, personal communication, July 27, 2018).

The net result of having an aging population is an increase in age related, disabling conditions. “The price we’re paying for extended life spans is a high rate of late-life disability” (Span, 2013). According to Harvard University’s Joint Center for Housing Studies, of households with

residents aged 80 and over, 71 percent experience household activity limitations, 45 percent have mobility limitations, and 34 percent experience self-care limitations. The overall aging of the population “will increase both the share and number of older adults with disabilities, particularly in the 80 and over group (Harvard University, 2016, p.42).

Population changes resulting from increases in both age and disability inevitably raise healthcare and economic policy considerations (Christensen et. al, 2009). While not unique to the United States, they demand formidable public policy decisions. The World Health Organization (WHO) stresses that policies on growing aged populations must take into account changing societal norms such as technology, urbanization, separation of generations and gender norms (World Health Organization, 2018).

“Societal aspirations change from era to era, incorporating new substantive realities and new popular beliefs and social values of particular cultures - historical political movements, national and ethnic shifts, and scientific understanding. The qualitative elements of old-old age are very different from understanding the elements of earlier life stages... What’s complicating is how [society] provides help and protection when physical, mental and social strengths and assets are declining. While preserving self-determination in the face of unremitting decline, a decline which extends longer and longer, we absorb and apply the benefits of medical care and treatment successfully and expand the size and nature of the population with disabilities” (E. Cohen, personal communication, July 27, 2018).

Maeckelberghe (2013) proposes one response to these expanding social changes and the ethical dilemmas that come with them - an ethical framework to help formulate public policy called “intergenerational solidarity”. According to the Organization for Economic Cooperation and Development (OECD), intergenerational solidarity is when

Generations have a positive view of one another or there is consensus between generations on the way forward. It is also a means to an end: a mechanism for supporting mutually beneficial exchanges, both monetary and nonmonetary, between generations (OECD Ministerial Meeting on Social Policy, 2011).

Approaches to public policy that respect the views of multiple generations, as in intergenerational solidarity, benefit from the wisdom of the generations, assuming we can find consensus. One solution offered by the co-author, is to invest in social technology, defined as technological trends with philosophical implications that use “all available knowledge and the digital tools at hand to transform society.” Social technology provides a “cross-sector approach to identify and tackle the foremost challenges facing humanity (“The social and environmental impact of technology,” 2020):

“We need significant investment in social technology. That will not come from traditional post higher education. We need more social research, not on the technological ends of social research but more on imaginative outcomes of social research - sociology, social work, political science. We have not advanced our social response to the technological age. We have not seen how we think about aging in American society. All theoretical thinking in Gerontology is relatively recent – one or two generations” (E. Cohen, personal communication, April 6, 2019).

Public Attitudes and Old Age

Public attitudes have not always been sympathetic toward older people and those with disabilities. For example, many believe the Americans with Disabilities Act (ADA) has had little impact on improving acceptance of people with disabilities by the public at large, even after 25 years. “Horrible stories of racial prejudice, violence and abuse are still all too common in the news and can cause us to wonder how far we have come since the 1960s” (Bradford, 2015). In fact, “determining whether the ADA achieved its goals has proven difficult for scholars”, primarily because the ADA has not gone as far as intended in changing public attitudes (Moroto & Pettinico, 2015).

The ADA covers all those with qualifying disabilities, regardless of age. So older adults with disabilities are equally eligible as their younger peers for accommodations under the law (Bachelder & Hilton, 1994). Similarly, misunderstandings aimed largely at younger, working aged people with disabilities are not dissimilar to those targeted toward older Americans. A recent framework analysis identifies public views of older people as generally negative, focusing on deterioration, stagnation, and dependency (Robbins, 2015). Further, older people are viewed as separate from society at large, while in competition for resources from other equally needy groups. The surveyed public believes older people have fewer family supports and are in some part responsible for their own wellness and financial stability; social determinants are not perceived to be relevant to their situation (Robbins, 2015).

Because aging is associated with so many of these complex social issues, greater numbers of people will be the subject of life and death ethical decisions as the population ages. Society must grapple with uncomfortable questions, particularly when it comes to living with the oldest old. One example, in the words of the co-author, is: “What are the costs and benefits to individuals, families, communities, and society-at-large, of death at particular ages” (E. Cohen, personal communication, September 25, 2018)? Ethical questions like this will be argued because they undergird our social policies.

As the oldest old become a larger segment of our society, discrimination and disparities are very real threats, with accompanying ethical challenges.

“[These threats] are of particular relevance to social justice because they may arise from intentional or unintentional discrimination or marginalization and, in any case, are likely to reinforce social disadvantage and vulnerability” (Braveman, Kumanyika, Fielding, Laveist, Borrell, Manderscheid, & Troutman, 2011).

A social justice imperative for older Americans is upon us, and sorely in need of attention, lest we repeat mistakes of our past. The struggle for equality has touched many groups in the United States, including racial, gender, religious, disabilities, and LGBTQ. The struggles are founded upon oppression, particularly noticeable if you happen to belong to one of the excluded groups. Yet, the social systems and structures that exert the oppression have inherent discrimination. They exercise pressure to maintain the status quo (Loewen & Pollard, 2010). While some of the hard fought protections now exist as a result of these social justice movements, ageism continues to be the subject of discrimination.

Social Role Valorization

Wolfensberger (2000) identified the societal tendency toward devaluation in his seminal work on “normalization”, later referred to as social role valorization. His schema has as its premise that “people’s welfare depends extensively on the social roles they occupy” (Wolfensberger, 2000). His work influenced the humane treatment of people with disabilities throughout the world. Wolfensberger became one of the most influential intellectuals and thinkers in the field of intellectual disability in the 20th century, thanks to his development of the normalization principle, his articulation of the theory of social role valorization, the creation of the tools ... for assessing the quality of services, and the vast knowledge mobilization undertaken by his Institute for Training at Syracuse University for nearly 40 years (Flynn,n.d.).

Disenfranchised groups are affected by devalued social roles, including people at extreme ends of the age spectrum and those who are impaired, or those with perceptibly negative body characteristics - the poor, those with few skills to offer or those who are unemployed and who are not participants in society (Wolfensberger, 2000, p. 107). Leulle (2018) points to the importance of maintaining (or even procuring) a valued social role, precisely because people who acquire cognitive disabilities tend to lose the [valued] roles they once held.

Investing in securing valued social roles ...or even creating new valued roles for [those with cognitive disabilities such as Alzheimer’s] would greatly enhance their opportunity to exercise moral agency, even if they are increasingly dependent on the support of others for their identification and orientation in the social practice of upholding a moral identity (p. 272).

Social discrimination resulting from disenfranchised roles has the potential to exacerbate inevitable and unpopular social policies emanating from a changing social order, including demands for more healthcare and strains on public benefits.

The issues are complex [and emphasize] that a society which marginalizes disabled people will discriminate against them anew, as new structures and forums for discrimination evolve. One necessary approach is to combat the discrimination with laws, but fundamental change in society remains necessary. Ruebin (n.d.)

Social disadvantage is difficult to regulate away, as we have seen with the ADA (Bradford, 2015). The outcomes of the ADA are even less clear when applied to the oldest old. In the words of the co-author:

Neither the world of old age nor the world of disability have looked systematically at the issue, largely I expect because the gerontology-oriented advocates were so caught up in the [assertion that] ‘old age is not a disability’ and the disability advocates were caught up in the fight for inclusion and participation of people with disabilities. And that fight was heavily influenced by the fight for participation in the labor force. For the elderly, however, the issue was how to remain a participant while undergoing constant increased disability, with virtually no interest in extending participation in the work force, when advancing age was accompanied by diminished strength, endurance, and stamina.... One group pushing to get INTO the workforce, and the other seeking to get OUT of the workforce (Personal communication, Eli Cohen, August 22, 2018).

In the United States and Europe, recent social programs have begun to emerge that favor community integration and address the social need for improved understanding of older people with disabilities. In the Netherlands, for example, students are offered free room and board in nursing homes in exchange for 30 hours per month of social contact with the residents (Reed, 2015). An example in the United States is Dementia Friendly America (DFA), representing a worldwide concept aimed at bolstering community tolerance, improving acceptance and embellishing community-based care options for individuals with dementia.

DFA is a national network of communities, organizations and individuals seeking to ensure that communities across the U.S. are equipped to support people living with dementia and their caregivers. Dementia friendly communities foster the ability of people living with dementia to remain in community and engage and thrive in day to day living. (Administration on Aging, n.d.)

But our society is still a long way from embracing and tolerating those with differences. Initiatives such as DFA advance acceptance and support for those who are aging with disabilities. We will be challenged to see inclusion in new ways as our population morphs in unprecedented ways. More efforts like these are necessary to counteract negative public misconceptions, and to address the widespread impact of our impending population changes. In our increasingly polarized society, finding social tolerance for those on the fringes is paramount.

Discussion

A population bubble like no other will emerge in the United States and the world over the next 30 years, and it will impact all of us in unforeseen ways. A central problem to emerge from this team's preliminary research is one of social roles. At each age in the lifespan, American citizens tend to have reasonably clear roles and expectations. People with significant disabilities, however, have historically been excluded from standard and valued roles – such as going to public schools, living in communities, and contributing to the workforce. As we have seen with recent research cited above (Robbins, 2015), the oldest old also experience devalued roles in our society.

Gerontology has not thought in parallel tracks with the professional world of disabilities. One of the major issues that has come from the disability world is, [people with disabilities] said ‘we want to participate’. But we don’t raise that question in aging. What are the ways to participate? We think about the senior center. That is not a way to participate in the larger society. The world of disability said we want to participate in the larger world (Personal communication, Eli Cohen, April 6, 2019).

Social policy focused on Wolfensberger’s Social Role Valorization (SRV) is therefore an area worthy of exploration. The SRV framework would target the creation of socially valued roles for older people, ones that award contribution and purpose. But before designing any such policy positions, it is essential to study, learn, and listen to our oldest citizens.

Conclusions and Future Study

Aging populations have latent strengths and contributions that society does not employ and may not comprehend. Lacking appropriate roles, older people may find themselves in social role

structures that eventually create a self-fulfilling prophecy. “Bereft of social opportunities, resources, or incentives, older people cannot utilize or sustain their mental or physical strengths and capacities (Riley & Riley, 1989, p. 5). Compounding this social mismatch, measuring the phenomenon may demand different ways of understanding the experiences of older people. “Growing old may very well mean a shift in emphasis on domains of importance for the perception of quality of life”, according to Borglin, Edberg & Halberg (2005). We may lack the appropriate knowledge to know what questions to ask or concepts to query. Hence, qualitative studies are necessary to ferret out assumptions and hypotheses in our discernment of the oldest old cohort.

In addition to incongruent roles society establishes for older persons, the probability of experiencing one or more disabilities becomes very high for people over 85. While age is not a disability, with very advanced age the two traits do indeed become highly correlated.

While the acquisition of disabilities is practically inevitable with age, negative social stereotypes continue to be the norm with both older people and with those having disabilities. Disability for the elderly may be different from younger and other population groups. This thought may be worthy of substantial exploration, with different outcomes, expectations, and probabilities, differences in the nature of disabilities and likely long and short-term outcomes, impact on the individual and others (spouse, family), and different [government] entitlements (e.g. education, public assistance programs, transportation, medical assistance, and so on). Given that ALL elderly have disabilities, and that virtually all elderly experience increasing disability, and they have perhaps decreased ability for rehabilitation, diminished caregiver resources, and diminished economic resources, what are the appropriate goals for addressing disability in late life?” (E. Cohen, personal communication, July 27, 2018).

If the oldest old experience social roles and disabilities differently than previous generations or their younger counterparts, what policy-related questions need to be answered? What approaches do we use to understand the apparent dynamic social roles of each generation’s aging phase? Can Social Role Valorization accurately frame the policy issues the world is facing in the advent of the oldest old population bubble? What role expectations are there for oldest old? How can we develop such roles? To what extent can age-related disabilities be addressed with social technology, adapted physical environments and public attitudes? What do these accommodations look like and to what end are they employed?

The rise and role of the oldest old must be better understood. The questions raised represent only a fragment of compelling issues and ethical considerations to inform near-future social and health policies in the United States. For the aged reaching the oldest old milestone and for society managing its impact, current social policies and programs are unsuitable. Our collective challenge is to understand the aging experience from those living it, so we can better provide support to them, their families, and society (Cohen, 2016). This is not optional, and we are considerably behind schedule. America and the world are ill prepared for the impending changes we face from a new social order. Likewise, Americans are ill prepared for living this long.

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Author Note

Special thanks to Dr. Jennifer Parker for her valuable feedback.

Correspondence concerning this article should be addressed to Anita Yuskauskas, Department of Health Policy and Administration, Penn State Lehigh Valley, 2809 Saucon Valley Road, Center Valley, PA 18034 Contact: auy10@pu.edu