

Autonomy, identity and health: defining quality of life in older age

Sara Kate Heide

Correspondence to

Sara Kate Heide, School of Medicine, New York Medical College, Valhalla, NY 10595-1524, USA; sheide@student.nymc.edu

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ABSTRACT

Defining quality of life is a difficult task as it is a subjective and personal experience. However, for the elderly, this definition is necessary for making complicated healthcare-related decisions. Commonly these decisions compare independence against safety or longevity against comfort. These choices are often not made in isolation, but with the help of a healthcare team. When the patient's concept of quality of life is miscommunicated, there is a risk of harm to the patient whose best interests are not well understood. In order to bridge this gap in understanding and unite seniors with their caretakers as a cohesive team, we need to establish a definition of quality of life. In this paper, my personal experiences with the elderly will be analysed along with five essays on the topic of ageing. These sources provide clear evidence that quality of life for seniors is majorly determined by the ability to preserve one's lifelong identity. When making difficult decisions in geriatric healthcare, this greater understanding of the determinants of life quality will allow treatments to best serve the elderly. Defining quality of life allows healthcare providers to shift the focus from minimising disability toward maximising ability. I believe this shift would provide seniors with better health outcomes and properly enhance the quality of their years.

For the last decade, I have been interested in defining the concept of quality of life for older adults. Throughout this time, seniors have taught me, through their words and their actions, that maintaining their lifelong sense of identity is the most crucial aspect in living a life of quality.

My work with seniors has made one thing abundantly clear: seniors are diverse. Of course, seniors have a variety of different occupations, ethnicities and religions, as does every age demographic. What makes the elderly so unique, however, is that they have diversity of age as well. It is very common for me to work with seniors in their 90s. These seniors are often visited by their children who are seniors themselves. Despite a parent and child fitting into the same broad category of elderly, their experience in the world is an entire generation apart. The great diversity that exists within this population lends itself to dramatic variations in values among the elderly. Despite this, these values are rarely listened to. I have often observed healthcare professionals and family members impose their own beliefs on the senior for whom they are caring. It is easy to see how this interpersonal misperception might negatively affect the elderly. Defining quality of life is difficult because of the vast individuality that exists between persons. For the elderly, this difficulty is compounded by ageism, which works

to silence the voices of seniors. The elderly are often faced with difficult decisions that force them to weigh the importance of independence versus safety or longevity versus comfort. These decisions can only be made with clear communication between the elderly and their caretakers on issues of quality of life. In an attempt to bridge this gap in understanding, I will look at five essays written by contemporary American writers on the topic of ageing. I have chosen these essays from *The New Yorker* because of their wide readership. I believe that these voices speak for American seniors on ideas about ageing and quality of life. These essays and my personal experiences will reveal commonly shared convictions of quality of life held by geriatric America. This greater understanding will aid patients, families and healthcare workers in navigating complex decisions in the realm of geriatric healthcare.

The first step in identifying what quality of life means to the elderly is to look at what it actually means to be elderly. When I tell others about my work with seniors, I am often asked: 'Do the seniors remember you?' This question acts as a subtle clue into the unconscious public biases that are held against seniors. In response, I explain that ageing is not synonymous with disease. The seniors who do not remember me, do not because of dementia, not because of age. Despite the great variety of health states among the elderly, people put seniors into a narrow class of people. I am always struck by this. We are taught to see people as individuals, but when it comes to the elderly, we categorise them irrespective of their vast differences. I have attributed these misconceptions to the fact that younger people have a difficult time understanding the lived experience of the elderly. I felt confident that this belief, that ageing and disease are interchangeable, would not be held by seniors themselves. It was much to my surprise to discover that this is not the case. Ceridwen Dovey touches on this in her essay 'What Old Age is Really Like'. Dovey highlights how many writers include illness as an essential part of the experience of being elderly. She quotes poet Adcock who says that 'old age began for her at the age of seventy, when she fell seriously ill for a period'.¹ This gives evidence to the idea that many people, including seniors, have this sense that illness is a defining feature of old age. This linguistic issue, that 'old' seems to refer to a subjective experience of illness, rather than an age-specific classification, could present an issue in geriatric care. If 'old' is defined subjectively, how then do we ensure that living facilities, geriatricians and senior communities are serving the demographic they intend to?



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If the prevailing definition of old age is in its relation to disability, we must then look at the effect that disability may have on life quality. The experience of one of my former assisted living residents, Mila, can illustrate this effect very well. At 104, Mila had no cognitive impairments and few physical restrictions. Despite being physically capable of moving, she was confined to her bed because of intense vertigo that she experienced upon standing or reading. Mila often expressed deep envy of those who did not have cognitive impairments as she felt tortured by a lack thereof. She was trapped inside a deteriorating body with an ever-curious mind. Conversely, at the same time that I was visiting Mila, I was working with several seniors who had cognitive impairments but few physical impairments. During an art lesson with patients with Alzheimer's disease, I saw one resident, Elisabeth, struggling greatly to participate. I came over and she explained to me through tears that she could not understand how to make art anymore. I told her we can do something else and gave her a pencil and some paper and asked if she wanted to write a story together. She wrote: 'this lady knows a lot, I struggle, because I can't see how to give answers to your great questions, I think the younger people are better at these things'. Not only does this imply an age bias that seniors hold against themselves; but it is in perfect juxtaposition to Mila's story. A disabled mind with a sound body and a disabled body with a sound mind achieve the same devastating result: a diminished quality of life.

Consequently, one might conclude that it is not the type of disability, but the presence of disability in general that influences life quality. Several essays, however, seem to describe a greater complexity to the disability/life quality relationship. Arthur Krystal discusses this intricacy in his essay, 'Why We Can't Tell the Truth About Aging'. Krystal identifies several literary works that question if life has any meaning at all once we reach old age.² This is a consistent theme in other essays as well, such as in Adam Gopnik's 'Can We Live Longer But Stay Younger?'. Gopnik explains that ageing and disability cannot be compatible with happiness. He describes how 'happiness is absorption and absorption is the opposite of willful attention'. For instance, if a person is preoccupied with how to eat as opposed to eating as an experience, they cannot truly enjoy it.³ However, this seems to be contradicted by other writers such as Roger Angell. Angell begins his essay, 'This Old Man', by listing the various ailments he suffers from (macular degeneration, herniated discs and so on). Despite these things, he maintains a quality of life. Angell describes how the 'pains and insults are bearable' because his relationships and hobbies keep him happy.⁴ Angell is not alone in this opinion. Krystal identifies many 'cheerful tidings' written by the elderly and mentions a 2011 Gallup survey that shows that happiness actually follows a U-shaped curve and thus increases as we move from middle to old age.² I recall a cheerful senior, Lorraine. Fellow residents referred to her as 'Tip-Top'. Whenever someone asked Lorraine how she was, she gaily responded "I am tip-top!" This optimism remained even after she sustained injuries from a devastating fall. When Lorraine eventually returned to my poetry club, she was in a wheelchair and had bandages on her head. Nonetheless, she eagerly volunteered to read her new poem aloud: "Today it's waffle and tea. I felt very happy. Also, there were blueberries. They looked very snappy". Lorraine's cheerfulness suggests that age and disability cannot be easily correlated to life quality. This challenges the method by which the current healthcare system operates. Too often, healthcare focuses on treating the disease rather than treating the person. While medical intervention is extremely necessary in many circumstances, it becomes a greater challenge in geriatric

settings. For seniors, devastating effects of certain medications, treatments or surgeries might leave them with other disabilities after the initial issue has been resolved. When determining which interventions should be pursued, an understanding of that patient's personal definition of life quality must be considered.

Seeing that age and disability are not defining features of life quality, there may be other major determinants that have been generally overlooked. Seniors have shown me that independence might be one of these crucial features. In Rebecca Mead's 'The Sense of Ending', the author discusses the importance of maintaining senior autonomy, even when the senior is suffering from a major health impairment such as Alzheimer's disease. Prioritising the patient's autonomy appears to drastically decrease their agitation, which we can assume correlates to enhanced life quality. In efforts to reduce the risk of falling, many care facilities physically or chemically restrict patients from walking around. In opposition to this, Mead quotes nursing home director Karen Mitchell who explains that 'we have to give residents the right to fall'.⁵ A resident I worked with, Emma, is an excellent example of a senior who prioritised independence over safety. Despite being legally blind, Emma refused services that would help her get downstairs in the morning. Instead, she counted the number of steps it took for her to get from her room to the elevator. Once inside, she felt the elevator wall and counted three buttons down. She successfully arrived at breakfast every morning without the help of a staff member. Emma was very conscious of her disabilities and understood her independence was accompanied by greater risk. She would tell me of days where the elevator was interrupted and she wandered around on the wrong floor. Nevertheless, she continued to take these risks in an effort to preserve her independence. This common cling for independence among seniors creates a disconnect between senior and caretaker. That is to say, recommendations by well-meaning professionals or family members might be poorly received by seniors who are placing a greater emphasis on independence than is realised. Gopnik discusses this when he describes how the emergency neck pendant system is extremely unpopular among the elderly. He cites a German study that found that even when subscribers fell and remained on the floor for more than 5 minutes, they did not use their devices to call for help 83% of the time.³ Widespread senior rejection of medically recommended equipment represents a failure of the healthcare system to successfully communicate, partner with and ultimately improve patient lives. Thus, it is crucial to uncover what geriatric notions are at play in creating a reluctance to accept these tools.

An analysis of these essays suggests that this issue might be rooted in hostility for a geriatric identity. As Elisabeth described when she said "...I think the young people are better at these things", seniors often have a negative connotation toward the concept of old age. Gopnik seems to agree that this identity crisis is what deters seniors from accepting the help they may need. As he describes, "Identity matters to us far more than utility."³ Effectively, senior-directed products are widely unpopular among the elderly. Perhaps as an effect of ageism, accepting the identity of a senior may feel like a confession of dependence on others and an inability to further contribute to society. As writer Angell describes, "[the elderly] are honored, respected, even loved, but not quite worth listening to anymore." Angell illustrates here how painfully aware seniors are of the negative attitudes held against them.⁴ I recall acts of ageism I have seen in my work. At an afternoon lunch with two elderly friends, I relive the embarrassment I felt when our waiter asked me how many menus we would like after I asked for a table for three. Despite the seniors having full ability to read, interpret and decide on

the menu, our waiter likely concluded that their old age and physical disabilities reflected poorly on their cognitive state. These constant assumptions about old age encourage seniors to fervently resist being viewed as incompetent. Seniors understand that they still possess meaningful talents, insights and skills. This understanding, however, is at odds with the negative stereotypes that society has created for them. Consequently, this allows for identity confusion among the elderly. Dovey quotes writer John Updike who confirms this when he describes how “approaching eighty, I sometimes see myself from a little distance, as a man I know, but not intimately.” Because seniors cannot fit into the confines of an elderly identity, a phenomenon, described by Dovey, exists such that seniors ‘tend to feel younger as [they] get older’. Dovey cites a 2009 survey on attitudes of old age to reveal that ‘almost half of the respondents aged 50 or more reported feeling at least 10 years younger than their actual age, while one-third of respondents aged 65 or more said they felt up to 19 years younger’.¹ This reveals that the personal feelings that seniors have about themselves are in contrast to what society is imposing on them.

If older adults cannot relate to the societally imposed elderly identity, then we must discover how they do think of themselves as this might be an influential factor on their quality of life. Dovey suggests that ‘who we are when we are old remains pretty close to who we were when we were young’.¹ This view is consistent with what I have observed while working in memory care facilities. Many seniors would desperately cling to their youthful responsibilities. One woman, Jenae, worked as a nurse in her younger years. Whenever a fellow resident felt sick, she was the first one to the scene. She would bring them water and would quickly alert the staff about the issue. This same phenomenon is described by Mead. She describes how one resident, a former retail worker, is constantly walking up and down the corridor. Despite being in apparent pain by the end of the day, she does not stop. ‘For decades, she had worked in retail, and she wasn’t going to stop walking just because she was in a dementia unit’.⁵ These accounts imply that despite the various changes that accompany the process of ageing, one’s lifelong sense of identity remains largely static.

Naturally, one’s ability to preserve this identity is a fundamental determinant of life quality. This explains the apparent variety in quality of life that exists among seniors, even when factors of age and disability level are accounted for. This clarifies how people, like Lorraine, maintained her ‘tip-top’ optimism despite her newfound disability. Lorraine was still able to engage in hobbies that maintained her sense of self. She wrote poetry, saw family and attended church. Her injuries were an inconvenience but they did not force her to re-examine her identity. Similarly, this explains why writer Angell maintained a high quality of life despite his physical ailments. Angell describes how he has taken up blogging, spends time reading and memorises short poems. Most notably, Angell is still being published in *The New Yorker*. Although Angell has had to adapt to a changing body and mind, he is maintaining the same role he always has—that of a writer.⁴ Conversely, this idea explains why certain seniors do not have a tolerable level of life quality. Elisabeth, a former kindergarten teacher, was deeply pained by the prospect of no longer understanding how to make art. Likewise, Mila, a lifelong learner, lost all will to live when her inner ear complications prevented her from hearing the television, reading books and leaving her room. This idea, that life quality depends heavily on the preservation of self-identity, is reinforced by Krystal. Krystal explains that ‘A contented old age probably depends on what we were like before we became old’. He uses this idea to describe why

some writers, such as Ezekiel J Emanuel, feel that they do not want to live past an age where they can no longer be productive, creative or original anymore. Krystal disagrees with this when he describes how this opinion applies only to ‘artists, intellectuals and scientists who will be pained by the prospect that their brain power and creativity may ebb in their twilight years, and not your average working stiff’.² In other words, if one’s identity lies in their ability to be productive, they will lose life quality if they lose productivity. However, if one’s identity is not rooted in productivity, this loss can be sufficiently adapted to.

My personal experiences in conjunction with these popular American essays have stressed this central theme: quality of life is defined as the ability to preserve one’s lifelong identity as they mature into old age. This preservation of identity is often challenged by newfound disabilities, the loss of independence and ageism. Life quality can be preserved despite these obstacles only if the senior’s central concept of self is also preserved. This greater understanding of geriatric convictions about the determinants of life quality is invaluable in helping to mend the interpersonal misconnect. These insights can help to improve health outcomes for seniors at both a micro and macro level. In thinking about large-scale improvements, healthcare providers might be more cognisant of the effects of certain interventions on the senior’s ability to perform identity-confirming activities. For example, psychotropic drugs are often prescribed to seniors in an attempt to calm the patient and reduce the risk of them walking around and falling. These prescriptions must be considered against what side effects can take away the individual patient’s quality of life. For the former retail worker who loved to walk all day, this chemical restriction might threaten her sense of identity and seriously diminish her life quality. As opposed to simply treating the disabilities that the physician views as most debilitating, more attention should be given to maximise the abilities that the senior views as most central in maintaining their identity. This approach will allow for a greater quality of life for those patients. It should be the physician’s goal to understand their patient’s identity as much as they understand their patient’s pathology.

While these wide-reaching suggestions for transforming the American healthcare system are important, grand changes often take root when they first take place in individuals. Ageism is a major influence in creating this intense cling by seniors to their youthful identity. Individuals can combat this by being conscious of the assumptions they may hold about seniors. Furthermore, during any engagement with a senior, one can focus on helping to maintain, rather than trying to challenge, their identity. For example, one senior I worked with, Freda, was a former teacher. She was comfortable with the role of a helper for she had acted in this role throughout her life. However, in the late stages of Alzheimer’s disease, she began to display outbursts of frustration. On one afternoon, Freda and I were sitting together, listening to a choir concert in the gathering lounge. Her sons came for a visit and asked her to follow them into a quieter room. Freda refused, she wanted to continue listening to the concert. Her children started insisting that she move, repeating how they ‘came all the way here for her’. This escalated the situation. Freda became more adamant about staying and her sons became increasingly upset. When they looked to me for help, I approached her with a warm smile. “Hi Freda, David, John and I are going into the café for a chat, we would love if you joined us.” Instantly, Freda stood up. All it took was a slight change in perspective. Asking Freda if she would like to help me, as opposed to demanding that she let me help her, changed her entire demeanour. At the root of Freda’s reluctance to leave was a dire need to preserve

her autonomy and her role as someone who helps others rather than someone who is in need of helping.

If our goal is to enhance senior life quality, the narrow societal construct of old age must be challenged. American seniors represent a uniquely diverse demographic that consists of multiple generations, hundreds of different nationalities and countless different occupied roles in society. While attempting to create a more effective healthcare system, we must first start by recognising and then preserving the individual identity that each senior has.

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REFERENCES

- 1 Dovey C. *What old age is really like*. New Yorker, 2015.
- 2 Krystal A. *Why We Can't Tell the Truth About Aging*. New Yorker, 2019.
- 3 Gopnik A. *Can we live longer but stay younger?* New Yorker, 2019.
- 4 Angell R. *This old man*. New Yorker, 2014.
- 5 Mead R. *The sense of an ending*. New Yorker, 2013.