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Growing Older With a Physical Disability: A Special Application of the Successful Aging Paradigm

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Abstract

Objectives: In the United States, the average age of people living with early-acquired physical disabilities is increasing. This cohort is said to be aging with disability and represents a unique population among older adults. Given recent policy efforts designed to merge aging and disability services, it is critical that models of "successful aging" include and are relevant to this population. However, many current definitions of successful aging emphasize avoidance of disability and high levels of physical function as necessary to well-being.

Method: In 9 focus groups, we examined perspectives of "successful aging" in 49 middle-aged and older individuals living with spinal cord injury, multiple sclerosis, muscular dystrophy, or postpolio syndrome. Transcripts were analyzed using a structured qualitative coding approach and Dedoose indexing software.

Results: Participants ranged in age from 45 to 80 years ($M = 62$) and had lived with their disability diagnosis for an average of 21 years. Analysis revealed 4 primary themes of successful aging: resilience/adaptation, autonomy, social connectedness, and physical health (including access to general and specialty healthcare).

Discussion: Results highlight the need for a nuanced application of the "successful aging" paradigm in this population.

Keywords: Physical disability—Rehabilitation—Successful aging

Aging With and Aging Into Disability

Over the past half century, we have witnessed a major demographic shift among people living with long-term, medical disabilities. The average age of individuals with conditions such as cerebral palsy, spinal cord injury (SCI), and multiple sclerosis (MS) is increasing (DeVivo & Chen, 2011; Strauss, Shavelle, Reynolds, Rosenbloom, & Day, 2007), due to population aging and to medical advances promoting early survivorship and improved disease control (Leray, Moreau, Fromont, & Edan, 2016; Strauss, Devivo, Paculdo, & Shavelle, 2006). More than half of individuals with MS are now over age 50 (Marrie, Yu, Blanchard, Leung, & Elliott, 2010), and in Western nations, 30% to 40% of adults with SCI are over 65 (Noonan et al., 2012). Those living into old age with disabilities acquired in early adulthood are said to "age with disability" (Verbrugge & Yang, 2002) and represent a growing population with unique healthcare needs.

As they grow older, individuals aging with disability will merge with formerly able-bodied adults who are aging into new impairments. Recent work has demonstrated that there are a number of unique trajectories of disability in people over 70 (e.g., Wolf, Freedman, Ondrich, Seplaki, & Spillman, 2015), but on average, disability onset for the general population is gradual and linear (Verbrugge, Brown, & Zajacova, 2016). These individuals are said to age into disability.

The degree of overlap between those aging *with* and those aging *into* physical disability is the topic of much discussion among researchers and policy makers. By definition, these two groups have distinct trajectories of ability across the life span. For able-bodied individuals, significant disability tends to develop late in life, whereas, for individuals with long-term impairments secondary to disease or injury, onset of disability is typically in the first four decades. This variability in onset and trajectory makes for important differences in the developmental life course. For example, people with certain disability conditions are less likely to marry (DeVivo & Richards, 1996), and may be less likely to have children (Verdier-Taillefer & Alperovitch, 1990), due to challenges with fertility, concerns about burdening children with caregiving responsibilities, or in some cases, worries about passing along a genetic condition (Pebdani, Johnson, & Amtmann, 2014; LaDonna, Ghavanini, & Venance, 2015). Even in disability conditions that are considered "static" (such as SCI), functional limitations are often not stable across the life span. Rather, there is now mounting evidence that the cumulative effects of living with a disability condition for many years contribute to premature declines in health (Imai, Kadowaki, & Aizawa, 2004). These may include early onset of chronic medical comorbidities such as diabetes and osteoarthritis (Jensen et al., 2013), as well as development and progression of "secondary conditions" like pain and fatigue, which, compared with adults without disabilities, are more severe, occur sooner, and stay elevated from midlife into older age (Cook, Molton, & Jensen, 2011; Molton et al., 2014). In conjunction with physical impairments due to the disability condition itself, these additional health problems increase the risk for involuntary early retirement (Denton, Plenderleith, & Chowhan, 2013), which is linked to poorer long-term financial and psychosocial trajectories (Schofield et al., 2012). For those aging with a disability, the complex interaction of these medical and social factors, and their timing and impact in the developmental life course, create an especially challenging environment for successful aging.

Despite these differences, those aging with and those aging into disabilities also have much in common. Both groups require integrated services that may include community-based rehabilitation and assistance with activities of daily living, both require support for community participation and transportation, and both benefit from efforts at community health promotion. Unfortunately, "cultural" or philosophical differences between aging and disability networks have historically been a barrier to effective partnership. As one author put it: "for the disabilities system, aging is a success; for the aging network, disability is a failure" (Ansello, 2004, p. 4).

One place in which this disconnection is apparent comes in the concept of "successful aging," a notion that is ubiquitous in gerontology but markedly absent from disability and rehabilitation science. Much discussion has focused on how best to define "successful aging" (Martinson & Berridge, 2015; Palmore, 1979; Strawbridge, Wallhagen, & Cohen, 2002), and models have included a variety of attributes, ranging from physiological function and the absence of disease, to longevity and emotional vitality (Depp & Jeste, 2006; Rowe & Kahn, 1997; Young, Fan, Parrish, & Frick, 2009). The idea that freedom from chronic illness or disability is necessary to age successfully has been the center of some debate (Bowling & Dieppe, 2005; Martinson & Berridge, 2015; Richardson, 2011; Strawbridge et al., 2002). However, this criterion is widespread in published definitions (Phelan & Larson, 2002) and is present in as many as 90% of empirical studies on the topic (Depp & Jeste, 2006). On one hand, it is easy to understand why this criterion is so pervasive. Most models of successful aging are designed to apply to formerly able-bodied adults, aging gradually into impairments. For these individuals, the prevention or delay of disability is certainly a worthwhile goal, with significant social and economic implications. However, in some ways this focus on avoidance of disability in later life embodies ableism, a set of beliefs that assign superior worth to people without disability. By their late 60s, as many as 45% of individuals will have two or more chronic health conditions (Freid, Berstein, & Bush, 2012), and the inference that a significant percentage of individuals could reach advanced old age without appreciable deterioration in health or function is simply not supported by population studies (Andersen-Ranberg, Schroll, & Jeune, 2001; Manton & Gu, 2001).

To those in the fields of disability and medical rehabilitation, the "freedom from chronic illness or disability" criterion is particularly troublesome. In the strictest sense, it would seem that individuals aging with disabling conditions cannot age successfully. In fact, individuals with disability have been overtly and specifically excluded from empirical studies of successful aging, including some supporting the MacArthur model (Berkman et al., 1993). For these individuals, ideas of "independence" and "a high level of physical and cognitive function" are nuanced, and the idea of "freedom from disability" is meaningless. Such criteria do not account for the wide range of accommodations and adaptations that individuals with disability may make to preserve function.

Given this, it is not surprising that models of successful aging, widespread in gerontology, have not been imported to rehabilitation science. In fact, we are aware of only a small handful of studies which directly address successful aging with early acquired disability (e.g., Ploughman, Austin, Murdoch, Kearney, Fisk, et al., 2012). Given the paucity of work on successful aging with disability, the purpose of the current study was to examine this concept from the perspective of people who have lived with physical impairments for decades, in the hopes of bringing this growing population into the conversation and guiding model formation.

Method

The present study was conducted under a University of Washington Rehabilitation Research and Training Center (RRTC) on "Healthy Aging and Physical Disability," funded by the Administration on Community Living. The

RRTC has a number of research goals, one of which is to conduct focus groups with middle-aged and older individuals with physical disabilities to identify aspects of successful aging in the context of disability and to inform other ongoing projects within the RRTC. In the present study, we report on nine of these focus groups (N = 49) conducted from May of 2009 through November of 2014. This long recruitment period reflects the longitudinal nature of the RRTC program (2008–2018).

Participants

Participants (N = 49) were at least 45 years of age and self-reported a physician confirmed diagnosis of SCI, MS, muscular dystrophy (MD), or postpolio syndrome (PPS). We recruited participants through a number of sources, including the University of Washington Department of Rehabilitation Medicine Participant Pool, the Rehabilitation Medicine clinics at the University of Washington Medical Center, and through national organizations such as the National MS Society. See Table 1 for selected demographic characteristics. The mean age of participants was 62 years (ranging from 45 to 80 years), and participants had been living with their disability diagnosis for an average of 21 years. Participants came from all areas of the United States, including rural and urban locations across 13 states.

Focus Group Data Collection

Nine focus groups, comprising four to eight participants, were conducted in person, or via telephone. This combined approach was selected to maximize the geographic distribution of participants and because telephone-based methods have a number of benefits for people with disabilities (including accommodation of participants who were homebound or for whom travel was difficult). This research was approved by the Institutional Review Board at the University of Washington and all participants received $25 for their participation.

Focus group discussions were moderated by trained facilitators. A discussion guide included questions such as: What does it means to you to age successfully with long-term physical disability? What resources do you have now that help you age well? Because these focus groups were also designed to inform other projects within the larger RRTC program, some focus groups contained additional content areas. For two groups (May, 2009), additional emphasis was placed on secondary health conditions and aging. For two more recent groups (Fall, 2014) greater emphasis was placed on the concept of "resilience" in coping with disability. However, all focus groups included core questions relevant to successful aging with disability. Focus groups lasted from 1 to 2 hr and were transcribed in real-time by a court reporter. Preliminary findings from early focus groups have been described elsewhere (Yorkston, McMullen, Molton, & Jensen, 2010). However, prior to this manuscript, these focus group data had not been analyzed cohesively in the context of "Successful Aging."

Table 1. Selected Demographics of Focus Group Participants

	n (%)
Gender	
Men	20 (41%)
Women	29 (59%)
Age[a]	
<50 years	7 (15%)
50–59 years	17 (35%)
60–69 years	13 (27%)
70+ years	11 (23%)
Race[a]	
White	46 (96%)
Black or African-American	2 (4%)
Education[a]	
High school or GED	8 (17%)
Some college or Technical/AA degree	5 (10%)
4-year college degree	16 (33%)
Advanced graduate degree	19 (40%)
Household income[a,b]	
<$20K	5 (13%)
$20–49K	15 (39%)
$50–99K	9 (24%)
$100 K+	8 (21%)
Refused	1 (3%)
Household composition[a,b]	
Lives alone	11 (30%)
Lives with housemate or roommate	1 (3%)
Lives with health-related companion	2 (5%)
Lives with spouse or partner	23 (62%)
Condition	
Muscular dystrophy	3 (6%)
Multiple sclerosis	21 (43%)
Postpolio syndrome	11 (22%)
Spinal cord injury	13 (27%)
Spinal cord injury and multiple sclerosis	1 (2%)
Years with condition[a]	
<5 years	2 (4%)
5–9 years	6 (13%)
10–19 years	13 (28%)
20+ years	26 (55%)

Notes: [a]At least one participant declined to answer this question (% based on number of participants who answered).
[b]This information was not requested of all focus groups, n = 38 (% based on number of participants who answered).

Bias and Rigor

Consistent with recommendations for qualitative research (Lincoln & Guba, 1985; Shenton, 2004), we relied on a combination of approaches to increase confidence in the authenticity of research findings (credibility) and to ensure that the data reflect the perspectives of the participants and not the researchers (confirmability). To reduce bias, moderators explained that the participants are the experts and the interviewer is interested in their experiences. We spoke with a range of individuals with different disabilities and life situations, and we encouraged participants to be frank and honest about their experiences. Questions were presented in a neutral language to minimize presuppositions. After each focus group, the interviewers debriefed and compared field notes to discuss what they viewed as salient information and how to best describe or characterize this information. The trustworthiness of the analysis was enhanced by an analyst triangulation approach which included discussions among an interdisciplinary team of researchers, fostering reflexivity and an attitude of awareness to the effect of the researcher on knowledge construction. These methods to reduce bias and enhance trustworthiness of the data are similar to those described elsewhere by this research group (Yorkston et al., 2010).

Data Analysis

Data were analyzed using steps recommended for qualitative research (Benner, 1994). After each focus group, transcripts and field notes were read several times in order to identify the main ideas expressed. A coding system was then developed to indicate important information related to “successful aging.” Quotes from each code or combination of codes were compiled and reviewed for discussion and interpretation. These codes were expanded into a formal codebook using open coding of transcript quotes, via indexing software (Dedoose, www.dedoose.com). After the formal code book was agreed upon, all transcripts were read and coded by at least two independent coders. Researchers then developed a framework of themes to interpret the coded data, through a constant comparative method of analysis where multiple cycles of reading and coding led to the development of common themes. Initial themes were reviewed until there was agreement that they accurately reflected the focus group discussion and served to answer research questions about the meaning and dimensions of successful aging with long-standing physical disability. This process continued until all researchers agreed that no new themes were emerging. The formal codebook is available from the study authors.

Results

Taken together, our focus groups suggested that successful aging with physical disability is a complex construct involving interdependent domains that are defined by the individual. Four common themes emerged from the analysis. These were (i) resilience and adaptation, (ii) autonomy, (iii) social connectedness, and (iv) physical health. These dimensions were seen as highly interrelated and connected such that “a little bit of each makes for a quality of life.” (M/SCI/71). (The notation following the quotes indicates sex/diagnosis/age.)

Theme 1: Resilience and Adaptation

“Resilience and Adaptation” included emotional mastery and the avoidance of negative chronic mood states, psychological resilience, and the ability to adapt to new circumstances. Participants saw themselves as aging “successfully” when they were able to experience pleasure, contentment, and reward from daily life and adapt to changes in health. One participant indicated, “Life is what you make it, and it can be a very beautiful thing if you just look for the beauty that is in your life, present every day, as opposed to looking for the problems.” (M/SCI/62)

Adaptation meant shifting or restructuring goals and was seen as an inevitable and important part of successful aging with disability:

> When I think about thriving, it’s not necessarily the way that I was before, and so it’s not so much removal of everything but a replacement, so it’s like, Okay, MS has caused this vacuum or this void in my life, but what else am I going to fill it with? (M/MS/51).

This process of adaptation developed over time: “I came to a point that—I just—I got smarter.·Not that I gave up and said, Okay, I’m not going to deal with that fight anymore, but I just said it’s not one that I need to be fighting anymore.” (M/MS/45)

This increased need for flexibility over time came as a surprise to some: “I think learning to be flexible... As it changes, I have to change my strategy. I am having to be more flexible than I thought.” (F/MS/59) The process of flexible adaptation was seen as coming with time and experience, as one participant suggested, “You get used to it. You adapt to it. You learn about it, and, as with aging, you get wiser.” (M/SCI/52) Importantly, the need to be flexible or adapt to an uncertain future was not always described in positive terms, and for some represented a significant struggle. “The hardest thing for me right now is this transition between the uncertainty, not knowing what’s coming, and trying to do—live your life.” (M/MS/46).

Theme 2: Autonomy

Autonomy was also seen as key to aging successfully. This involved the ability to maintain a sense of personal agency, self-efficacy and choice as one aged. Importantly, autonomy as described by participants was not the same as what might be called “independence,” in that many examples focused on the ability to make choices regarding how one interacted with others (e.g., directing caregivers), how one participated in valued activities, or how one selected adaptive equipment.

Choice-as-autonomy was described as beginning early in the trajectory of disability. For example, a participant described life after SCI and how the experience fostered in him a greater sense of self-determination. He indicated that after the injury,

> "…life had stopped. And that was a real big barrier to me… It wasn't until I made the decision that I'm still here I'm still the same person I was prior to my injury, and it's a choice." (M/SCI/62)

In many cases, emphasis was placed on the importance of having options and a sense of choice in how to engage in meaningful activities within one's abilities. Autonomy in this sense also meant the ability to direct and participate in one's caregiving and to have a voice in housing and other decisions. Statements about autonomy often overlapped with those describing resilience and flexibility, as individuals emphasized the importance of individual choice in adapting to new circumstances. "I find my motivation probably helps me more than anything, because I try not to look at what I can't do but to look and see how I can do what I want to do." (F/PPS/80) One participant summed the discussion up by saying, "the goal is definitely to be able to do what you want to do. Not necessarily what you have to do." (F/MS/57)

Theme 3: Social Connectedness

The availability of support or assistance from a variety of sources was a common theme, and participants frequently described aspects of social connectedness as core to successful aging. This domain included the degree to which one is interacting with ones' friends, family, and social environment, and with others who shared disability, including the social support those connections provide. A 68-year-old man with MD put it succinctly: "If it weren't for my wife I wouldn't want to be here, period." (M/MD/68)

Consistent with the broader disabilities literature (Crabtree, Haslam, Postmes, & Haslam, 2010; Salmon, 2013), participants reported a need to connect with others both with and without disability. Connection to others who shared a disability diagnosis was seen as important for practical reasons. A 79-year-old woman with PPS had this example: "I have found that a lot of people don't know what is available… someone [a peer] told me that I could go to the nursing home and that they had a warm pool." Disability-specific connections were also emphasized as a way to foster unity and disability identity. A middle-aged participant with MS summed up the need for greater community support for others with the same diagnosis:

> "I know if there was… an MS community garden, and this is where people with MS come, and they all garden together… that could be very gratifying, and everybody from being in a chair to being upright like myself can participate in that." (M/56/MS)

Importantly, some participants reported ambivalence about connecting with others who share their disability condition, based on historical stigma. It was suggested that this perspective might shift with age. "Growing up, the goal for… polio survivors was to be normal and to hide the handicap… As I've gotten much older over the last 10 years, I've become a little more open to attending support groups…" (F/PPS/67)

Several participants also described a sense of having to take a proactive role in their social relationships in order to overcome isolation, "Because a lot of times you do feel like you're alone." (M/MS/56)

Theme 4: Physical Health

The final domain of successful aging reflected an individual's current symptoms, wellness, and access to services to promote or maintain physical health. This domain contained two interrelated subdomains: (i) maintenance of current physical health and (ii) access to appropriate healthcare.

Maintenance of current physical health

Management of secondary conditions (including pain, spasticity, and fatigue) and ameliorating their impact on valued activities was seen as essential to successful aging. For middle-aged participants, the negative impact of secondary conditions included involuntary retirement. A 51-year-old woman with MS reported "With such limited eyesight and the loss of cognition, …when I lost my sense in my fingers… I said I had to retire from being a nurse." Similarly, one man reported: "I really tried to do that for three years, and it was the hardest three years of my life.·I mean… I was on so many medications that I had to detox.· and then I lost the job anyways." (M/MS/56) For participants who were past working age, the impact of secondary conditions was also significant. A 79-year-old woman with PPS described a cycle of pain, insomnia, and fatigue as the primary detractor of her quality of life, over and above functional limitations caused by her disease.

Access to appropriate healthcare

Participants agreed that managing secondary health conditions required access to appropriate healthcare resources. Access included availability (of primary and rehabilitation care, as well as community wellness and exercise programs), accessibility (in terms of environmental and transportation barriers, as well as appropriate medical equipment in physician offices), and appropriateness (including providers who are knowledgeable about disability conditions and community programs that were adapted or tailored for people with disabilities).

Participants in our focus groups reported challenges in all three of these access areas. One participant described the importance of "a community without steps" and a built environment free of mobility barriers as essential to his participation in healthcare (M/SCI/56). Participants also lamented a lack of community providers who were knowledgeable about their disability conditions and frequently felt that they had more information about their disability condition than their family physician. "Most general practitioners don't know where to send people and for what services there are. I have a general practitioner that I like and have gone to for years, but he says, 'I am too busy to research polio. You research it and I'll be glad to send you'." (F/PPS/80)

Despite this perceived lack of provider knowledge, participants also reported that an open attitude was more important to them than specialty expertise. "If you find a doctor who is open-minded, who says, these are your symptoms, let's address those symptoms, you don't have to understand the complete disability." (F/PPS/67)

Discussion

To our knowledge, this study is one of only a handful to address the notion of "successful aging" in persons with long-term physical disabilities. The themes emerging from focus group discussion suggest that successful aging with long-term physical disability is a complex construct, comprising a number of interrelating domains including psychological resiliency and adaptation, autonomy, social connectedness, and the availability of appropriate, accessible healthcare.

In many ways, these results confirm other qualitative work in the medical rehabilitation and disability literature. For example, Ploughman and colleagues (Ploughman, Austin, Murdoch, Kearney, Fisk, et al., 2012; Ploughman, Austin, Murdoch, Kearney, Godwin, et al., 2012) have reported themes of self-management, social engagement, healthcare, resilience, and independence at home as important to healthy aging in people with MS. Our results in most domains are similar, although participants in our groups tended to emphasize decisional autonomy in making adaptations and working with others to maintain activities, over "independence" per se. However, the desired outcome (greater participation in valued activities, in a living situation of one's choosing) is likely the same. Given that Ploughman's work involved 18 individuals in one geographic location, our results may be seen as replication and extension, including a larger sample and geographic range.

We also see many similarities to the general Gerontology literature. The domains of successful aging identified by our participants overlap with those from biomedical approaches (e.g., maintaining ones physical health; Rowe & Kahn, 1997; Seeman et al., 1994) and with psychosocial approaches (e.g., maintaining social connections; Bowling & Dieppe, 2005) to successful aging. In fact, participants in our focus groups observed this commonality and were not especially troubled by it:

> "…that's the thing about MS. It's like most people will get all the symptoms of MS eventually. It's just that we get it much, much earlier. And, you know, in some ways the same things that work with the geriatric population probably would work with MS as well." (M/MS/58)

Similarities also existed in specific themes. For example, elements of Resilience and Adaptation map closely onto what has been called loss-based selection or the restructuring of one's goal system, by giving up unattainable goals and developing new ones (P. B. Baltes & Baltes, 1990). P. B. Baltes and Baltes (1990) have developed a model in which an individual ages successfully in spite of declining physical health, through a process of selective optimization and compensation. More recently, Young, Frick, and Phelan (2009) proposed a multidimensional model of "successful aging" that allows for healthy aging in the presence of chronic medical conditions.

This leads naturally to the question—is successful aging any different for people with long-term physical disabilities? Based on our focus groups and the literature on aging and disability, we argue that although the domains of successful aging may be similar for this population, they exist in a somewhat unique social and medical context and should be appreciated in a nuanced way.

One important difference comes in trajectory of ability. People aging with long-term disability experience limitations earlier and have a trajectory of function that intersects with other normative tasks of the developmental life course. Although this is often profoundly interfering (e.g., early retirement due to poor health; Schofield et al., 2012), participants also described a kind of inoculating effect of early disability on coping with later impairments, seeing themselves as pioneers of aging: "You are used to adversity. It's how you grow up." (F: PPS: 67) They suggest that they may be better equipped than people without disability because they have "a certain resilience of view" and have had experienced disability when "you're young, able to adapt." (M: SCI: 56) (Yorkston et al., 2010)

The observation that elements of successful aging in disability overlap with successful aging in general, but have unique contextual nuances, was also true for the other themes of our focus groups. For example, our finding that adaptation is important to successful aging is not especially novel, as this maps closely onto the idea of "loss-based selection" (P. B. Baltes & Baltes, 1990). However, our findings also emphasized coping with unpredictable losses in the context of medical uncertainty and avoiding comparisons to one's "predisability" self.

Autonomy was another important theme. Importantly, autonomy was not equated with independence, consistent with previous observations in people with disability (Moody, 1992). Our participants emphasized that for them, autonomy meant the ability to exercise choices, but that this often required negotiation and assistance from others. This has been described in the rehabilitation literature as "assisted autonomy" (Janicki & Ansello, 2000) and is seen as a way to preserve human dignity in the face of worsening physical function (Ansello, 2004). Likely, the importance of assisted autonomy, rather than independence, is shared by the general older adult population, but may have special meaning in persons aging with physical disability. These individuals may need to negotiate with and train caregivers at younger ages and in disability-specific domains (e.g., structured bowel/bladder management programs and transfers) and may depend on others for transportation and community participation. This theme may also reflect a cohort effect, as patients with chronic conditions increasingly reject a paternalistic style of medical decision making and wish to be more active in their care (Newton, Scambler, & Asimakopoulou, 2011).

The fact that Social Connectedness emerged as a theme was not surprising. Certainly this is not unique to disability—although a review of social support literature in older adults is beyond the scope of this manuscript, it is clear that social connection is a protective factor for older adults across contexts (Schwarzbach, Luppa, Forstmeier, Konig, & Riedel-Heller, 2014) and is consistent with an emphasis on social relations taken from many models of successful aging, including the MacArthur model. This is also true in disability in general, where perceived social support is generally associated with positive psychological functioning (Müller, Peter, Cieza, & Geyh, 2012). However, one unique nuance is that for people aging with disability conditions, social and family relationships may be completely fused with caregiving (Holicky & Charlifue, 1999), given that spouses and family members often provide the majority of care (Post, Bloemen, & de Witte, 2005), and from earlier ages. Social connection to others is therefore uniquely associated with health, community participation, and healthcare access in this population. In our focus groups, individuals emphasized the need for both social support in general and from other people with disabilities, which created a sense of kinship, opportunities to exchange symptom management strategies, and mutual belonging. This is consistent with other work in which people describe unique benefits of interacting with others who share disability conditions (Salmon, 2013; Tabuteau-Harrison, Haslam, & Mewse, 2016), including "insider" humor, and a buffer to disability stigma.

Physical health was clearly important to our participants. However, in an important departure from models that highlight avoidance of disease (Rowe & Kahn, 1997), participants did not emphasize the absence of disability or illness as necessary to successful aging. Rather, they saw mobility limitations as expected and additional loss of function as inevitable. They desired ways to ameliorate the impact of those declines on their ability to participate in valued activities. This tendency to see maintenance of physical health as a means to achieve greater participation, rather than an end unto itself, fits with models of successful aging that allow for the presence of chronic medical conditions (e.g., Young, Frick, et al., 2009).

Another variation came in that our participants were less concerned with their primary diagnosis and more concerned about the impact of secondary health conditions, including chronic pain and fatigue, associated with their disability. In many cases, these may be more impairing than the primary disability itself and represent significant barriers to community participation.

To manage health and secondary conditions, our participants desired access to appropriate healthcare and saw this as necessary for successful aging. Their concern is well founded—certain access issues have been identified as disproportionately affecting persons with disabilities. These include physical and transportation barriers, limited access to assistive technology, equipment, medications, specialists, and personal care attendants, physical inaccessibility of offices, examining rooms, or equipment, and patient perceived barriers, such as poor attitudes and a lack of knowledge about disabilities among providers (Harrington, Hirsch, Hammond, Norton, & Bockenek, 2009; Veltman, Stewart, Tardif, & Branigan, 2001). Overcoming these barriers will require what Rowe & Kahn (2015) refer to as a "reengineering of core social institutions" to ensure equitable access.

Elements of Successful Aging With Disability

For this population, successful aging might be defined as using psychological, social support, and healthcare resources to live a life consistent with personal values in the context of disability. Based on these focus groups, we propose that indicators of successful aging in adults with longstanding disabilities might include the following elements:

(1) Psychological resilience, including the absence of negative mood states and the ability to experience pleasure, contentment, and reward from daily life
(2) Psychological adaptability and flexibility, including an openness to selection, optimization, and compensation and to changes brought about by the disability condition
(3) Autonomy and choice in decision making, including a high degree of personal efficacy in directing one's care and choosing activities (distinct from "independence")
(4) Social and community participation and positive connection to others, both with and without disability
(5) Medical care that is accessible, available, and appropriate, with an emphasis on management of secondary health conditions
(6) Effective compensation for functional impairments, within an individual's particular abilities, and based on their own goals and expectations for activity

Limitations and Future Directions

This work has a number of limitations. Most notably, these data were collected over a long period of time (approximately 5 years), as part of a larger research effort. This introduces a number of potential confounds (e.g., time effects) that can contribute to study bias. The focus groups in this study were also conducted with mixed modes, including a combination of telephone and in-person sessions, and it is possible that individuals in an in-person group may have felt more comfortable and been more forthcoming than those participating in a conference call. Although all participants were asked to address issues related to healthy aging and disability, certain focus groups also contained particular content areas (resilience and secondary conditions in aging), which may have contributed to an artificial emphasis. The wide geographic dispersion of participants in this study may be seen as a strength and a limitation—although it maximized representation from different geographic areas, it also introduced confounds that could not be controlled in the context of qualitative analysis. Finally, this study included individuals with both static and progressive conditions, which may have influenced perspectives on successful aging.

Clearly, a number of disease-related and demographic factors could influence successful aging and disability, including finances, degree of social support, gender differences, and differences in disease trajectory. Further work should evaluate the impact of those factors on successful aging with long-term disability.

Conclusions

As the population of western nations becomes older, it is imperative that our interventions are formed on science that is inclusive and relevant to older adults of various ability levels. Successful aging for adults with disabilities exists in a unique context. Older adults with long-term disabilities may offer an important perspective on successful aging, not because they have managed to avoid disability, but rather because they have lived it. In their recent review, Rowe and Kahn (2015) state that "Older people have much to offer, including their accrued knowledge, stability, their heightened capacity for synthetic problem solving, their increased ability to manage conflicts, and their ability to take the perspectives of other age groups into account." This focus on "human capital" is perhaps especially salient in the context of people with long-term disability. Through their experiences of impairment, ableism, adaptation, and resilience, these individuals have accrued knowledge of great relevance to adults aging into new impairments. Given the changing demographics of disability in the United States, a greater awareness of these perspectives will advance the relevance and inclusiveness of the "successful aging" paradigm for all older adults.

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Author Contributions

I. R. Molton planned and directed the study, supervised data collection, and was the primary writer of the manuscript. K. M. Yorkston performed qualitative analyses, provided data interpretation, and contributed substantially to the writing of the manuscript.

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