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Ageing successfully with a physical disability: the views and experiences of people ageing with spinal cord injury or post-polio syndrome

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Abstract

Average lifespans for people with physical disabilities are increasing; yet there is limited knowledge about their perceptions of what it means to age well. The criteria for Rowe and Kahn's influential model of successful ageing effectively preclude people ageing with a long-term disability. Several authors have attempted to develop more-inclusive models of successful ageing. The aim of this study was to explore what successful ageing means for people ageing with either spinal cord injury (SCI) or post-polio syndrome (PPS). We used an emic-based methodology, and recruited from Australia 17 participants aged 40–78 years. Nine participants (one male, eight female) had acquired poliomyelitis in childhood and experienced PPS, and eight participants (seven male, one female) had acquired an SCI 15 or more years ago. We used semi-structured interviews to elicit participants' views on the dimensions important to ageing successfully with a disability, and analysed the transcripts using inductive thematic analysis. We identified eight themes, which related to: (1) maintaining physical health, (2) retaining cognitive abilities, (3) a sense of safety and security, (4) being treated with fairness and respect, (5) positive psychological resources, (6) independence and autonomy, (7) social engagement and participation in community and (8) a sense of purpose. We used the findings to construct a multi-dimensional successful ageing model for those ageing with SCI or PPS. The model includes insights from lay perspectives that further illustrate the role broader society plays in supporting or hindering individuals to age successfully, and has implications for health-care and government services.

Keywords: inclusive; qualitative; society; socio-political

Introduction

Rowe and Kahn (1997) first conceptualised successful ageing as comprising three essential elements: (1) freedom from disease or disability; (2) maintaining high levels of cognitive functioning; and (3) active engagement in life. One controversial aspect of this model is that it effectively precludes individuals with a pre-existing disability or medical condition, who would therefore be considered to be ageing pathologically (Bülow and Söderqvist 2014). As with earlier models and theories of ageing (Putnam 2002), Rowe and Kahn's model can therefore be seen as inherently exclusionary to people with physical disabilities, even though many older people with disabilities consider themselves to be ageing well (Romo *et al.* 2013). Rowe and Khan's model has also been criticised for placing the responsibility to age well on the individual, with insufficient emphasis on the roles that social, political and environmental factors have on an individual's ability to age successfully (Calasanti and King 2021). Thus, critics of the model have argued that naming the avoidance of disability and disease 'success' may demean those with disabilities (Holstein and Minkler 2003), and encourage judgement and the promotion of negative stereotypes (Stone 2003). Others have highlighted a need for the model to adopt a lifecourse perspective that takes into account the context in which a person has developed and aged (Stowe and Cooney 2015). Given that approximately 16 per cent of the world's population, or around 1.3 billion people worldwide, live with some form of disability (World Health Organization 2023a), and increasing numbers are now living beyond age 65 (Bryce *et al.* 2021), it is therefore essential to understand what ageing successfully means from a less ableist perspective (Martinson and Berridge 2015).

Since the introduction of Rowe and Kahn's model, much of the subsequent successful ageing discourse has focussed on the importance of factors others than physical health and ability. For instance, in contrast to academic models of successful ageing, lay people have defined successful ageing as comprising a much broader range of factors, including psycho-social constructs such as happiness, independence and financial security (Feng and Straughan 2017; Iwamasa and Iwasaki 2011); self-acceptance and engagement with life (Reichstadt *et al.* 2010); and maintaining a good social network (Jopp *et al.* 2014). This discrepancy is important as models of successful ageing contribute to decisions about public policy and service development for older people (Blix and Ågotnes 2023; Foster and Walker 2015; Thuesen *et al.* 2023). Indeed, Rowe and Khan's emphasis on the maintenance of functional ability is reflected in the strategic aims of the World Health Organization and United Nations' 'Decade of Healthy Ageing' initiative (World Health Organization 2023b), although these aims do also recognise the contribution of environmental characteristics to an individual's level of functioning.

Our understanding of what it means to age well therefore needs to capture a diverse range of older people's perspectives. To date, though, research into what it means to age successfully with a disability has been largely overlooked (Minkler and Fadem 2002; Putnam 2002), and the voices of those ageing with a disability are largely missing from conversations about ageing well (Martinson and Berridge, 2015). Indeed, the biomedical positioning of Rowe and Khan's successful ageing model could be considered at ideological odds with the discipline of critical disability studies, which emphasises the

social, political and environmental causes of disability (Reaume 2014): something that perhaps accounts for the relative absence of successful ageing research within this field (Molton and Yorkston 2017). In addition, the small literature on ageing well with a lifelong disability that is available has tended to focus on those ageing with intellectual disabilities, rather than physical, sensory or motor disabilities (Smith et al. 2024). There is therefore a need to better understand what successful ageing means to people ageing with a physical disability.

Ageing with a long-term disability

People ageing with a long-term disability present from birth, childhood or early to mid-adulthood can be conceptually distinguished from people who acquire disability in later life, after having lived a relatively disability-free life until mid- or late adulthood (Leahy 2021). For instance, Clarke and Latham (2014) found that individuals who aged *with* a disability were exposed to accumulating social, psychological, economic and health inequalities over the lifecourse relative to those who aged *into* disability as they got older. People ageing with a disability are also likely to share common experiences of disability-related stigma, othering, and other forms of discrimination throughout their lives (Turner 2006). Despite these shared experiences, there is also immeasurable variability in the life experiences of those with different types of disability: many of these will influence the way that an individual subsequently approaches later life. For example, Grassman et al. (2012) report how retirement age was experienced differently according to whether or not a person's disability had prevented them from working. In particular, many of those who were retiring from the workforce mourned the 'affirmation of normality' that paid work had provided them, whereas those who had not worked owing to their disability were more likely to see retirement as a time when they became more similar to their age-group peers.

Two populations that have previously been highlighted as having quite different trajectories of disability are those growing older with the progressive condition of post-polio syndrome (PPS), of whom there are estimated to be 10 million–20 million worldwide (Baj et al. 2015), and those who have experienced a sudden onset disability owing to a traumatic spinal cord injury (SCI) at a relatively early stage of life (Kemp 2005). Individuals living with SCI and PPS can now be expected to live into their sixties and beyond (Yorkston et al. 2010). The views and experiences of middle-aged and older people living with SCI and PPS are therefore useful for informing models of what it means to age successfully with a disability.

Models of ageing successfully with a disability

Some researchers have begun to explore more-inclusive models of ageing successfully. For example, Young et al. (2009) proposed a conceptual model that takes into account the illness limitations typically acquired as an individual ages. Young et al. (2009, pp. 88–89) suggested that successful ageing should be defined as the ability to use physically and socially adaptive strategies 'to achieve a sense of wellbeing, high self-assessed quality of life, and a sense of personal fulfilment even in the context of illness and disability'. Importantly, though, this proposed model was developed by a panel of experts without input from those who have personal experience of ageing into,

or with, a disability. Thus, while this perspective addresses the limited dimensionality in the Rowe and Kahn (1997) model, it does little to address the paucity of research drawing on the experiences of those who are ageing with a disability. In contrast, Molton and Yorkston (2017) gathered the views of 49 middle-aged and older adults who were ageing with a disability, and identified four dimensions that participants considered to be important for successful ageing: autonomy; physical health; social connectedness; and resilience and adaption. This work therefore suggests a model of successful ageing that overlaps with, and yet is subtly distinct from, models of successful ageing reported by able-bodied participants. For instance, the authors reported that, while social connectedness has been shown to be an important component of successful ageing in able-bodied populations, the social connections described by participants in their study were more likely to include others with disabilities; this had the effect simultaneously of strengthening and scaffolding an individual's disability identity and providing a sense of unity with others in a similar position (Molton and Yorkston 2017).

Although Molton and Yorkston's (2017) study provides some unique insights into the meaning of successful ageing to people ageing with disabilities, the authors themselves point out a number of limitations that may have restricted the conclusions that could be drawn. In particular, the focus groups were undertaken as part of a broader series of studies, and some of the interview schedules focussed on quite specific aspects of successful ageing, which may have limited the breadth of the perspectives shared. In addition, the use of telephone interviews and in-person group sessions may have led to some participants feeling less comfortable about sharing their views. The lack of non-verbal cues in telephone-based sessions may also have led to relevant communicative information or opportunities for follow-up questions being missed, thus further restricting the richness of the data collected.

Research aim

The aim of this study was therefore to increase our understanding of what successful ageing means to people living with a physical disability through the use of one-to-one, in-person, semi-structured interviews. To capture a more diverse range of experiences, including from those experiencing disability associated with ageing as well as those ageing with a longer-term disability (Leahy 2021), we recruited participants who were experiencing progressive, age-related impairment owing to PPS, as well as those who had experienced a more sudden onset of impairment following an SCI in early or mid-life.

Methods

Participants

The study followed an emic-based methodology, which means that it focussed on the study of phenomena within a single cultural group, rather than looking to identify commonalities in phenomena across different cultures (Fetvadjev and van de Vijver 2015). As such, all participants were recruited from Australia.

Participants were eligible for inclusion in this study if they had a good level of English and capacity to provide informed consent, and were either: (1) aged

Table 1. Demographic details of study participants

Participants with PPS (n=9)		Participants with SCI (n=8)	
Gender	Age (years)	Gender	Age (years)
F	72	M	52
F	70	M	76
F	76	M	45
M	72	M	62
F	60	M	51
F	78	M	50
F	66	M	49
F	65	F	40
F	72	-	-

50–80 years and experiencing PPS as a result of contracting polio in childhood or (2) aged 40–80 years and having acquired an SCI at least 15 years ago, and before the age of 35 years. The different age criteria for the two groups reflect the fact that historical survival rates following an SCI were very low, with average life expectancy following an SCI in 1945 being only two years (Kemp 2005). Although current life expectancy following an SCI has improved significantly (Kemp 2005), long-term SCI populations are still typically younger than those with PPS (Becker 2006; National Spinal Cord Injury Statistical Center 2013). Lower-age cut-offs are also more appropriate when examining the age-related experiences of people who are ageing with a disability owing to the more accelerated ageing that these populations often experience (Leahy 2021; Reber et al. 2023).

Participants were recruited via hardcopy newsletters and the social media pages of Independence Australia (a not-for-profit organization providing support services to individuals with a physical disability) and AQA Spire (which provides peer-support services for people with an SCI). Snowballing techniques and word of mouth were also used to recruit additional participants. As potential participants notified the researchers of their interest, they were screened by email or telephone to ensure that they met the criteria for inclusion. The final sample comprised 17 older adults (nine females and eight males), aged 40–78 years (mean age = 62.1 years). Nine of these had PPS (eight females and one male; mean age = 70.1 years) and eight had SCI (one female and seven males; mean age = 53.1 years). The demographic characteristics of each participant are shown in Table 1.

Procedure

A qualitative study, using a grounded theoretical approach, allowed for the exploration of what it means to age successfully with SCI or PPS, bridging the gap between current conceptions of successful ageing and the reality for individuals who are ageing with a long-standing physical disability. This approach allowed multiple voices to be heard so that a deeper understanding could be garnered. Ethical approval for the study was granted by the University of Melbourne Human Research Ethics Committee (UMHREC).

Semi-structured interviews were used to elicit participants' thoughts and feelings, and to capture the variability and complexity of each individual's experiences. In order to reduce the risk of artificially restricting, or biasing, the range of topics covered, open questions were used that allowed participants to direct the flow of the conversation within the semi-structured interview framework. Questions were first developed by the research team on the basis of both prior research on successful ageing and the lead author's clinical experience working with individuals with physical disabilities. These questions were then reviewed and refined by specialist advisors at Independence Australia and Spire to ensure that wording was appropriate. The interview schedule included questions about how well/successfully the participant felt they had aged so far; what personal strengths they thought had helped them as they had aged; and what obstacles, if any, had hindered their ability to age successfully. To reduce bias, questions were presented verbally in a neutral language; the interviewer made it clear that the participant was considered the expert in this topic, and that the study team were interested in their experience. Interviews were conducted in participants' homes, in private spaces in public libraries or at participants' offices. They ranged between 48 and 270 minutes in length ($M = 102.70$, standard deviation (SD) = 55.35 minutes). Information about the study and a consent form were emailed to participants prior to the interview, and all participants provided written informed consent before commencement of the interviews. All interviews were audio-recorded and later transcribed verbatim.

Data analysis

Interview transcripts were analysed using the qualitative analysis software NVivo 11. Inductive thematic analysis was used to develop a preliminary model of what it means to age successfully with a long-term disability. This involved the first author listening to interviews and re-reading field notes to identify important moments, prior to interpretation (Boyatzis 1998). A coding system was then developed to capture important information related to successful ageing. Quotes relating to each code, or combination of codes, were compiled and then reviewed by the second and third authors for discussion and interpretation. Key themes were subsequently identified based on the extent to which they related to the research question and/or their prominence as a patterned response within the data.

At each stage of the coding process the results were reviewed by the research team for coherence and consistency, and to minimise bias. Data were analysed on an ongoing basis, using a constant comparative method of analysis that involved multiple cycles of reading and coding. Data from each group (PPS and SCI) were initially analysed separately to allow any differences in thematic structure to emerge. Themes from each group were subsequently compared and, as they were found to be broadly comparable, combined, although similarities and differences of expression between groups were captured and reported in the narrative. The results were also shared with a subset of participants who agreed that the themes identified were accurate and appropriate interpretations of the points discussed.

Findings

Overall, eight themes were identified from the analysis that described separable, interacting dimensions considered to be important to ageing successfully with SCI or PPS (Table 2). These were to do with (1) maintaining physical health, (2) retaining cognitive abilities, (3) a sense of safety and security, (4) being treated with fairness and respect, (5) positive psychological resources, (6) independence and autonomy, (7) social engagement and participation in community and (8) a sense of purpose. Four of these themes (physical health, positive psychological resources, independence and autonomy, and social engagement and participation in community) were very similar to the four dimensions previously reported by Molton and Yorkston (2017). As such, these themes are not described in detail here, although representative quotes are included in Table 2, and more detailed descriptions can be found in the Supplementary Material.

Of the other four themes that emerged, two (a sense of safety and security and being treated with fairness and respect) have not previously been reported in regard to successful ageing, and the other two (retaining cognitive abilities and a sense of purpose) have previously been found to be important in research among able-bodied participants (Feng and Straughan 2017; Iwamasa and Iwasaki 2011) but have not been reported in research into successful ageing with a disability. These four themes are therefore described in detail in what follows.

Theme 2: Retaining cognitive abilities

Several participants in both groups referred to the importance of remaining cognitively healthy and aware. For instance, participants explained that ‘the mind is the key to everything, you know’ (M/SCI/50) and that ‘if you’re not in a home, if your brain is functioning properly, that’s ageing well’ (F/PPS/60), highlighting the centrality of cognitive function to successful ageing. Another participant explained, ‘My mind is the only thing I have now, but I can use it to run my life’ (M/SCI/50), which suggests the particular role of cognitive function in supporting the ability to live independently, especially in the face of higher levels of physical disability. Other participants discussed how their ability to learn new skills enhanced their self-esteem: ‘[Y]ou learn to do things on your own, your own way, and you feel good about it’ (M/SCI/52). This highlights another potential role of cognitive function in supporting people to boost their mood and age well.

Participants also described how their cognitive abilities help them to age well by managing difficulties, reducing stress and maximising the opportunities available to them. For instance, one participant stated that ‘ageing well is getting clever in your old age, doing things the easy way’ (M/PPS/72), which highlights a role for cognitive function in being able to compensate for altered levels of physical functioning. Other participants discussed how cognitive abilities were important for ageing well as they helped them to plan ahead and evaluate situations to reduce risk and possible threats to self, or to make the most of their reduced energy:

Table 2. Illustrative quotes for each of the eight themes

Theme	Theme name	Illustrative quotes
1	Maintaining physical health	'Your health is your wealth.' (M/SCI/52) 'I'm really protective now of my legs and I want to make sure that I can be as mobile as possible.' (F/PPS/72)
2	Retaining cognitive abilities	'That's how I get through life. I sit and plan.' (M/PPS/72)
3	A sense of safety and security	'Aged care packages do not allow for much equipment, which is a big worry for people like myself.' (F/PPS/70)
4	Being treated with fairness and respect	'They show off: "We are a council that has such and such a number of people with disabilities." Well, what are you doing for that, to make the place accessible?' (F/SCI/40)
5	Positive psychological resources	'I don't fear infirmity ... or illness or death or anything or ... Because I think I'm already disabled, you know? And I don't care. I have learned to cope with that, so any more pain or suffering: I don't care, I can answer that, you know?' (M/SCI/50) 'This is really important in ageing well, erm, is, is not letting your brain take you off into downward spirals. Erm, that is so easy to listen to it instead of saying, "No, I'm not going down that path."'" (F/PPS/72)
6	Independence and autonomy	'I am quite independent. I just worry that I might lose my independence as I get older. And most people who are ageing, you know, not only those who are disabled have that ...' (M/SCI/50) 'I think probably it goes back to the early years of when you were having, in hospital, you've got no control over what happens to you.' (F/PPS/66)
7	Social engagement and participation in community	'I think anyone ... whether they be disabled or non-disabled, needs to have stimulation to keep them active, and ageing well.' (F/SCI/40) '... when you have [a] good support system around you. I think that's so important for mindset.' (F/PPS/60)
8	A sense of purpose	'Feeling useful is important. So if you can do something, then that's good. Find something that you're interested in.' (F/PPS/72)

Realising your limitations is the major thing. If you know what you are able to do and work within it, and don't try and go out of the boundaries, because you pay for it ... so you are thinking all the time and trying to mitigate anything that is going to have an adverse effect on you. (F/PPS/78)

Such reflections again demonstrate the role of cognitive function in being able to respond adaptively to potential challenges.

The majority of participants also reported actively trying to exercise and stretch their minds using cognitive activities such as crosswords, reading or exploring new fields of interest, in the hopes of staving off dementia for as long as possible: 'I try and learn something new every day. I have always done that to keep the brain active' (M/PPS/72). Such active attempts to use and maintain cognitive functions further demonstrate their importance to participants.

Theme 3: A sense of safety and security

Participants reflected on the importance of achieving a sense of safety and security as one ages. This included having access to adequate income and secure housing that is tailored to their current and future mobility and disability needs. Achieving and maintaining an adequate level of income revealed a sense of vulnerability that many of the participants, particularly those reliant on government services, felt in terms of being able to access appropriate help as they age. Participants from both groups, for example, recognised the importance of having sufficient income to enable individuals with disabilities to participate in society, remain socially connected and pay for new equipment and home modifications as necessary. As one participant explained:

If you have the money you can do tennis, you can do this, you can do that, and you are not worried. But if you don't have the resources then yes, the things are there but I cannot access them. So don't expect me to be ageing well when I don't even have the money to pay my rent. (F/SCI/40)

Another participant summarised the point by stating that 'it helps to not be desperately poor. I know that certainly affects people's outcomes when they get older' (M/SCI/62).

In fact, the majority of participants raised concerns about having sufficient funds in later life to be able to pay for home adaptations and mobility aids so that they could remain in their homes for as long as possible. Participants who were reliant on government assistance expressed uncertainty and frustration about changes to government funding that were perceived as 'taking all of the support systems away' (F/PPS/60) and thus affected their ability to remain independent and to afford the necessary assistance or equipment they would need as their conditions worsened. One participant with SCI explained that they were 'lucky enough that I have the support with TAC [the Transport Accident Commission, which pays benefits to people injured in Australia in transport accidents], but a lot of my friends, they don't. So, they don't have the carers maybe that I have, or the services that I have' (F/SCI/40). This reflects a broad difference between the groups, as SCI participants were generally more likely to be in a financially stable position than their PPS counterparts owing to this kind of insurance pay-out to which PPS members were not entitled.

The majority of participants also noted the importance of being able to access assistance to remain in their own homes for as long as possible. As one participant explained, 'losing my environment, ... is one of the things I actually fear most' (M/SCI/50). As part of this, participants raised the need for appropriate supported housing options to be available for older people with disabilities as they age and their conditions potentially worsen. One of the younger participants of the study discussed

some of these options as being 'like small units that are part of a condo where I think they have doctors available and things like [that]. But each person lives independent, [and] they have the alarm things in case there is an emergency' (F/SCI/40). This quote shows how even middle-aged participants were aware of the importance of planning ahead, and identifying how and where future care needs can be met, in order to ensure their future safety and security.

Theme 4: Being treated with fairness and respect

Participants universally raised being treated with fairness and respect as important for ageing successfully with a physical disability; they described how this helped to buffer and protect psychological resources such as positive affect, and to boost resilience. For instance, one participant explained that 'it's mainly people who understand your limitations, and not sympathetic, in sympathy forms, but understand and have empathy' (M/72/PPS). Reports like this show how participants saw themselves as being better able to age successfully when they were supported by others who recognised the person, their strengths and their experiences, and not just their perceived deficits.

Other participants spoke of instances when they had felt that the actions of other people had devalued their efforts, or discriminated against them, and it had affected their ability to age well. As one participant observed, 'I can think of five marginalisations that I've suffered from without even trying to think' (F/65/PPS). Other participants recalled disappointing interactions with health-care professionals and government agencies. For example, one participant discussed his experience of a rehabilitation centre:

[T]here is a lot of negative attitudes in some of those places as well. They try and write you off, tell you that you are never going to be able to do this or that. And in some cases people rebel against that and achieve a lot, in which case it is okay. But other people, I find it is a bit sad that they just sort of say 'oh okay' and then give up. (M/SCI/49)

Similarly, another participant described an interaction with a government customer service centre:

[Y]es I'm this old, and I've got this disability, and there is somebody at the other end of the phone who should be helping me who don't care two sh*ts because it's just a job for them. No, it's not a job. If you're going to take that job, be more compassionate and be more caring! (F/PPS/60)

Both of those examples make clear how interactions with people who showed little apparent respect or recognition for the participant could have negative impacts on their self-esteem, sense of worth and motivation.

Participants with PPS, in particular, described feeling forgotten, overlooked and disregarded by government and welfare agencies, with one participant observing that "End Polio Now" [an initiative by Rotary International to fund global polio vaccinations for children] has made us even more invisible' (F/PPS/72). Most recently these

concerns had been exacerbated by changes to (Australian) government disability funding that cuts off at age 65. This is problematic for many as 'most of us [polio survivors] were born pre-1950. And, and it's just been really insulting!' (F/PPS/72). Another participant reported how this was 'a bit degrading. I mean you're not a second-class citizen and I mean we're about the only people in the community that don't get help from the government' (F/PPS/78). These experiences reflect the frustration that many people with disabilities experience owing to what are perceived as unfair and prejudicial rules.

Government policies such as these were seen by some participants as the ultimate betrayal and rejection, after they had worked hard for many years despite their disability. As one participant explained: 'I worked all my life, well for as long as I could, and I contributed, and I didn't get any benefits from it. That makes me angry' (F/PPS/78). Indeed, PPS participants universally reported difficulties accessing the help that they needed in a timely and sensitive manner. For some people, interactions such as these reflected the prejudices and negative attitudes they had experienced since childhood, where 'there was a lot of fear about polio. And people in the street, you know, avoided you, and that sort of stuff' (F/PPS/72). One participant talked about 'being told as children, the state doesn't want a bunch of cripples, you get out there and be normal' (F/PPS/72), suggesting that early-life experiences of disability and 'otherness' may have had an impact on people's views and experiences of ageing well at later points in the lifespan.

Participants across both groups also spoke about how the wider community needed to be more cognisant of the needs of those with disabilities, to create a fairer and more inclusive society. Problems with accessing buildings, transport and disabled parking were cited as hindrances to being able to participate in community activities. For instance, one participant recounted the experience of a young person with polio who used a wheelchair who 'got herself a job as an accountant; fronted up for the job; couldn't get into the building' (F/PPS/72). Other participants reported similar problems when trying to access health centres, office units and even retirement homes.

Some participants raised concerns about relationships and sexuality not being recognised as important for disabled persons, and the impact this could have if they were forced through ill-health to move into supported living facilities. For instance, one participant observed that 'people with a disability are seen as asexual' (F/PPS/66), highlighting a perceived lack of awareness from others that those with disabilities might have sexual needs.

Theme 8: A sense of purpose

Retaining a sense of purpose, be it through advocacy, volunteering or being involved in community activities, was considered to be another important element of successful ageing: 'I think if you have purpose and you have, then everything else comes nicely with ageing' (M/SCI/50). It was seen as providing a number of benefits for participants. For instance, one participant described how 'successful ageing to me would be like getting out, helping other people, not letting it get you down, thinking positive' (M/SCI/76), demonstrating the potential role of purposeful activities in enhancing mood and providing activity and social engagement. Another participant explained how 'being useful is incredibly important' (F/PPS/72), showing the high value placed

on being able to contribute to society. Other reported benefits of purposeful activities included gaining a sense of fulfilment and feeling valued, respected and significant.

Another key way for many participants to find purpose was by sharing their knowledge and expertise to help others: ‘the mentor thing that we do now, that is the best, that is the best’ (M/SCI/52). Participants described being able to see others benefit from their efforts: ‘I’ve seen first-hand how it’s helped people’ (M/SCI/52). One participant who volunteered at a centre for disabled adults stated, ‘I just love them [those who attend] so much that it makes me want to get up and out of bed in the morning and go there’ (F/PPS/70), which shows the positive impact that these kinds of activity could have on social relationships and feeling a sense of purpose in life.

One participant summed up the important role of purpose as follows: ‘Well, if they have been successful in doing something positive, something that they are proud of. Something they are happy they have done, something they have enjoyed doing. Instead of just ageing’ (F/PPS/78). This suggests that engaging in meaningful, purposeful activities is a key factor that can transform ageing into ageing well.

Proposed dimensions of successful ageing with a disability

The eight themes described in our results reveal a broad range of intrinsic and extrinsic factors that had positive or negative influences on participants’ perceived ability to age successfully. [Figure 1](#) positions each of the eight themes as separate, yet interrelated and interacting dimensions, each of which helps to support an individual with SCI or PPS to age successfully. We propose that each dimension acts like a spoke in a wheel, protecting the hub and facilitating an individual’s sense of ageing successfully. Extrinsic social, political and cultural influences are depicted in the model as an encompassing circle, or tyre that surrounds the wheel, cushioning individuals from negative influences such as environmental deprivation, perceived discrimination, stress and social exclusion. Thus, the proposed model shown here acknowledges that, in many cases, the ability to age successfully with a physical disability is not wholly dependent on the individual but also requires, and is influenced by, the availability of adequate resources such as quality health care, accessible and inclusive services, financial security, appropriate housing options and opportunities for social participation. For without these necessities being met, one is seldom able to prioritise looking after one’s health and wellbeing.

Discussion

Using an emic-based inductive research methodology, this study investigated the concept of successful ageing as perceived by individuals ageing with SCI or PPS. Overall, eight key themes were identified from the data. Four of these – relating to maintaining physical health; positive psychological resources; independence and autonomy; and social engagement and participation in community – were similar to those previously reported by Molton and Yorkston (2017) in their study of people ageing with a disability. Two – retaining cognitive abilities; and a sense of purpose – have previously been found to be important in research among the general population (Feng and Straughan 2017; Iwamasa and Iwasaki 2011), although they have not been reported

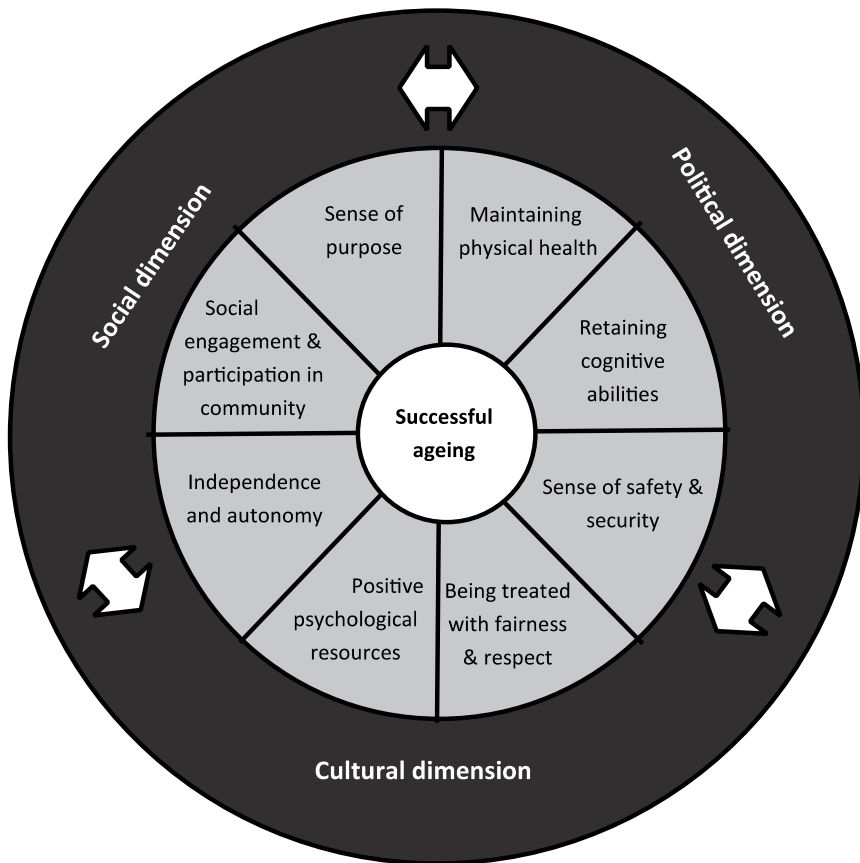


Figure 1. Diagrammatic representation of the factors important for successful ageing with SCI or PPS.

in research into successful ageing with a disability. Finally, two new themes – having a sense of safety and security; and being treated with fairness and respect – were identified from the interviews, neither of which is prominent in the successful ageing literature.

Overwhelmingly, study participants discussed successful ageing in terms of multiple, interacting aspects of life encompassing a range of individual, social, cultural and political factors. As such, the preliminary model shown in [Figure 1](#) takes into consideration insights from participants relating to their perceived position within broader social, cultural and political systems and processes. Participants, for example, described how interactions between individual resources and wider political and social factors can exert a positive or negative influence on their ability to age successfully, thus providing accumulating evidence for the need to adopt a biopsychosocial perspective (Iwamasa and Iwasaki 2011; Jopp et al. 2014; Reichstadt et al. 2010) to develop more-inclusive models of successful ageing that are relevant to those ageing with a disability.

There are some notable differences between the findings of this study and studies of successful ageing within the general population. For instance, of the 105 successful ageing models identified in a systematic review by Cosco *et al.* (2014), none identified the importance of being treated respectfully, and only 6 identified 'extrinsic factors' such as finances as being important to successful ageing. In our sample, however, a sense of safety and security, which encompassed access to secure housing and an adequate level of income to pay for basic needs including medical and/or mobility equipment and home assistance, was mentioned by approximately three-quarters of participants. While these factors have been largely omitted from descriptions of successful ageing in the general population (Cosco *et al.* 2014), research has consistently shown the pervasive, deleterious effect that low socio-economic status can have on an individual's health and wellbeing over the long term (Adler and Newman 2002). Certainly, Hank (2011) found that, at a population level, lower socio-economic status significantly constrained opportunities, and reduced the odds of ageing successfully. The particular salience of this issue in our results could be explained by a number of factors. First, it may reflect the reduced opportunity to work that many people living with a disability may experience (Nowrouzi-Kia *et al.* 2022): a factor that ultimately impacts their level of savings as they enter old age (Clarke and Latham 2014). Second, it could reflect their increased likelihood of having to rely on government funding and external providers for mobility aids and other equipment, much of which is being progressively scaled back and altered as governments seek to limit their financial exposure to an ageing population (Blix and Ågotnes 2023; Foster and Walker 2015). Third, it could stem from the important role that personal finance plays in paying for support that can minimise experiences of disability, and maximise independence and autonomy (Leahy 2021). Irrespective of the reasons for the prominence of this issue, it was clear from participants' comments that inadequate income and insecure housing options create a sense of uncertainty and vulnerability that affects an individual's capacity to actively engage and participate in society, ultimately interacting with participants' sense of being marginalised, demonised and treated unfairly.

It is perhaps not surprising, therefore, that being treated with fairness and respect was also seen as important by participants in our study, despite it not being a prominent issue within successful ageing models developed from the general population (Cosco *et al.* 2014). Indeed, research by Bahm and Forchuk (2009) found that 53 per cent of participants with a physical disability reported experiencing at least some degree of stigma or discrimination related to their impairment, which may lead to negative self-perceptions (Green *et al.* 2005). The essence of one's sense of self is, after all, developed in reference to the reactions of others (Green *et al.* 2005). If, for example, we observe that others devalue our efforts and treat us as less than a whole person, this can naturally have an impact on our self-worth and our ability to age successfully. Importantly, the overwhelming majority of participants in our study showed evidence of having overcome the stigma they had experienced. Many, for example, discussed early discrimination experiences as proactively stimulating psychological resources, galvanising their desire to fight against perceived unjust treatment. Other studies exploring responses to stigma in disabled populations have found a similar response, which suggests that, for some, rather than accepting negative stereotypes, these experiences can motivate a determination to overcome adversity by

embracing positive self-perceptions (Shih 2004). Certainly, the role of positive psychological functioning was emphasised by participants in both our study and that of Molton and Yorkston (2017), with all participants endorsing the importance of positive self-esteem, self-acceptance and adaptive coping skills such as resilience and tenacity.

Another significant finding in our study was the high value that participants placed on retaining their cognitive functions. Thus, while many studies conducted within the general population endorse the importance of cognitive function in broad, rather abstract terms (Iwamasa and Iwasaki 2011; Phelan et al. 2004), and have suggested that brain health is a lower priority than many other health issues (Nussbaum 2011), many participants in our study emphasised the need to retain cognitive functioning as paramount. For instance, participants described cognitive functioning as fundamental to maintaining their sense of self and identity, and discussed their reliance on cognitive abilities to plan ahead, negotiate everyday obstacles and advocate for their rights, including their right to age in place. Participants' expressed need to retain high levels of cognitive functioning was also considered crucial for retaining their autonomy, which may reflect the perception that their own desires are often overlooked and disregarded by others. Indeed, the results of our study suggest that cognitive function was closely linked to a desire to retain control and autonomy over future health and housing decisions, possibly owing to concerns that if they were to lose these skills then they would likely be moved into supported housing that was ill-equipped to deal with individuals with physical disabilities. While the results of our study do not allow us to draw strong conclusions about the relative importance of each successful ageing factor in comparison with other populations, they do suggest that maintaining cognitive function is a high priority for many people ageing with a physical disability.

Participants also reported how activities that promote a sense of purpose and usefulness were especially valuable in assisting people to age successfully, listing a number of benefits that they derive from their efforts, such as a sense of accomplishment, the development of strong social support networks, enhanced self-awareness and self-realisation, as well as a sense of contentment, gratitude and acceptance of themselves. This is in line with findings from the McArthur study of successful ageing in the general population, and suggests that a sense of usefulness may exert a protective effect on disability and mortality (Gruenewald et al. 2007). Additionally, similar to an earlier study by Raymond et al. (2014), social roles and the ability to engage in pro-social behaviour to help others were identified as key sources of dignity for people ageing with a physical disability. This suggests that interventions and programmes that provide social support and connection, as well as opportunities for engagement in meaningful activities, would be universally beneficial for ageing well. Importantly, the participants' descriptions of these activities and their benefits closely reflected perspectives addressed in the lifespan models of Baltes and Baltes (1990) and Erikson (1982) in terms of how they focussed their available abilities and resources on the areas of life they considered most meaningful. Our findings support these lifespan models and add to them by acknowledging the additional influences of the wider socio-political environment on an individual's perceived 'success'.

Limitations

There are some limitations to this work. First, we recruited participants through non-random sampling methods, and so we may not have captured the full diversity of the population. In particular, the model that emerged from this study may not be relevant to those who have not adapted to their disabilities as well, are in poor health, are more isolated or are unable or unwilling to participate in such research. Second, all participants lived within 150 kilometres of Melbourne, Australia. Given the emerging role that wider social and political systems appear to play in successful ageing, it might be suggested that the narrow geographical distribution of our participant group may not be fully representative of the wider range of different disability experiences and influences. Finally, although our findings reflect the experiences of people with two very different types of physical disability (SCI and PPS), we cannot be sure how well they reflect the experiences of people ageing with other types of physical disability. These may differ in important ways such as in the time and cause of onset and progression; the nature of impairment(s); and the presence of complications (Grassman *et al.* 2012). The model and the conclusions that we have drawn from these data may therefore not be applicable to people ageing with other types of physical disability.

Conclusion

The proposed preliminary model adds two new dimensions – being treated with fairness and respect and achieving a sense of safety and security – to existing models of successful ageing (Cosco *et al.* 2014), as well as an additional supporting layer that depicts the impact that socio-political influences can have on an individual's ability to age successfully with a physical disability. Additionally, it is suggested that, rather than being a hierarchy, successful ageing with SCI or PPS may be better captured by the concept of a wheel (as shown in Figure 1), where each spoke provides a means of supporting individuals to age successfully, when surrounded by appropriate political, social and community resources.

Future research should seek to address the relevance of this model with a broader cross-section of individuals with different types of disability, as well as with the able-bodied population, in order to elucidate any similarities or differences in the presence, nature and/or rank ordering of the identified factors. This will be an important step if research is to develop a more-inclusive and generalisable model of successful ageing that can be used to support and improve future policy efforts aimed at bettering the circumstances in which all people live and age. Overall, adopting a multifaceted perspective by considering insights from disciplines such as medicine, rehabilitation, psychology and sociology will result not only in more comprehensive and inclusive models of successful ageing but also, in the long run, in better policies that support more individuals to experience successful ageing. Findings from such studies will also assist researchers and professionals who provide services to older adults to develop interventions aimed at promoting successful ageing.

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