The Experience of Ageing for People with Physical Impairments
- with **particular reference to polio survivors**

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Abstract

A 2012 study explored the life experiences of a group using a qualitative approach. In depth interviews were conducted with 10 Victorians, aged between 51 and 84 years, who had lived with polio related or other impairments for at least 40 years. An inductive thematic analysis was undertaken. A relationship was found between the adaptive strategies which participants developed, as they moved through life phases and impairment stages. The implications of the emergence of a cyclical process of adaptation across the life course and particularly in respect of aging, delivery of aged care services and social workers in this sector are discussed.

Background

Since the initial research was undertaken, and an abridged version was published (1), the author has continued her research and participated in advocacy for Post Polio Victoria.

An increasing number of Australia's ageing population are aging with long-term physical impairments (2).
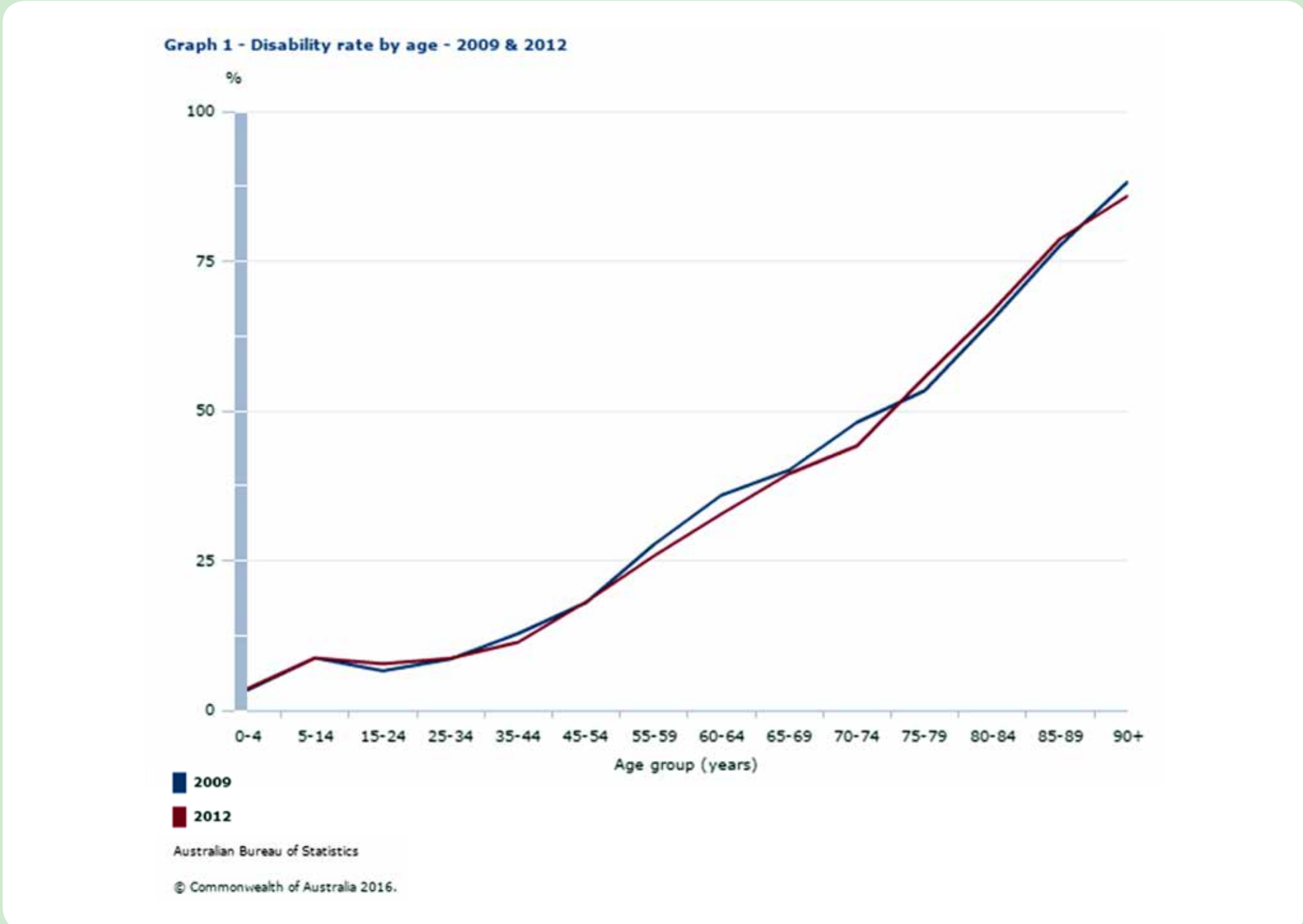
18.5%, or 1 in 5 Australians, reported having a disability. 88% of those people, 3.7 million, had a specific limitation or restriction affecting self care, mobility, communication, education or employment.

Amongst these statistics are many polio survivors have developed post polio syndrome (2) and/or Late Effects of Polio (3). Older survivors also cope with ageing processes. It is unclear how many Australians had polio, however one estimate is 150,000.(4)

Initial Research Question

What are the experiences of people ageing with long-term physical impairment?

The purpose of research was to gain the perspective of people with disabilities. Why? Ageing processes are complicated by progression of an impairment or the onset of age related health conditions. Ageing of this cohort raises many issues about the purpose and the design of health and support services to maximise quality of life outcomes. Not only is the view of potential customers important for service development, it is integral to Australia's implementation of the UN Convention on the Rights of Disabled Persons.

A literature review revealed little published material on the experiences of ageing for people with disabilities.

Methodology

A qualitative research approach enabled learning from participants who lived within a complex social context. Grounded theory methodology was chosen as it was directly related to respondents' expressed experiences and thoughts. A purposive sample of sixteen self-selected people was gained from invitations posted in two disability issues newsletters and two email discussion lists. Ten participants met the additional criteria of having reached the age of fifty years, and of having lived with impairment for forty years, within the state of Victoria, and were included in the study. Impairments included polio, ataxia, porphyria, muscular dystrophy and cerebral palsy. Data was collected by two in depth interviews, coded and analysed to discover thematic relationships.

Respondents came from very different social backgrounds and their upbringing ranged from rural childhood to urban living. Their education varied from primary school level to tertiary qualifications. Their ages varied from eighty-four to fifty-one years at the time of the first interview. Their impairments stemmed from varied diagnostic conditions and they all demonstrated ability to cope with significant physical adversity. They have lived through a similar historic period. Participants experienced similar socio-contextual elements in relation to community attitudes to people with impairments. They are people very different from each other who have divergent life styles and beliefs. However they suffered common difficulties, not all of their own making, which affected their participation in society.

Findings

A. A major finding of this study not previously reported is the adoption of different adaptive strategies by people with physical impairments to the progressive changes in impairments over their life course. As participants moved through life course phases and impairment stages their adaptive strategies changed. These strategies were heavily influenced by the Australian social contextual periods.

B. The life course perspective was useful in exploring social challenges confronted by participants.

Polio survivors came from this

And this

To now

Cooper 1987 The beginnings of the Polio Network in Victoria, Australia

C. Understanding the social context of life phases and impairment stages is crucial to assisting polio survivors

D. People became expert in management of their impairments while moving through the same life stages as their non-disabled peers. They demonstrated strong adaptive abilities and as new physical limitations were perceived, their strategies changed to enable achievement of life goals.

E. Four cycles of adaptation to life phases and impairment stages were identified.

At each phase of their life course participants had to deal with normative social expectations associated with adulthood, middle age and later life. Life course phases and related impairment stages occurred at the same time in the lives of participants. Coping with these challenges was complicated by a discriminatory social environment. This study suggests all participants used similar adaptive strategies which differed according to each phase of their life courses and all went through four similar adaptive cycles to deal with stages of impairment. Self-determination was a strategy which retained a constant value throughout all cycles.
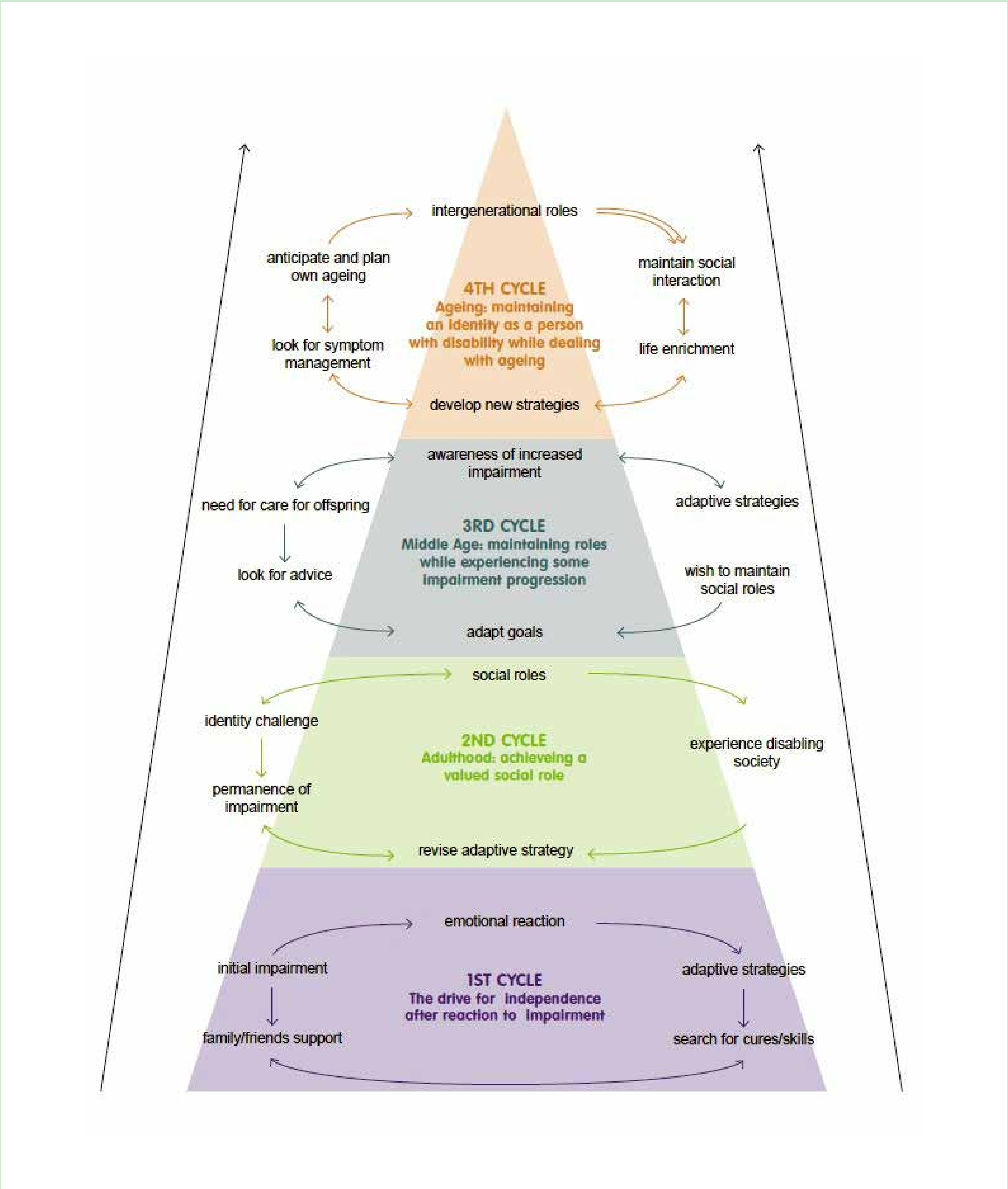

Figure 1. Representation of life stages and adaptive cycles

Some strategies, such as the use of anger, used in earlier cycles, recurred briefly in later cycles and were used effectively. Each cycle was characterised by the need for participants to confront their experience of impairment, deal with its' progression or additional health conditions, cope with discriminatory social contexts and meet normative role expectations. The move from one cycle to another and the development of new or revised sub-goals, was marked primarily by additional challenges posed by normative life course phases and altered physical function. The latter was due to impairment progression leading to reduced physical abilities or other conditions which may be associated with ageing.

Strategic thinking and goal setting enabled participants to work through serious physical and social crises. Figure 4 has a triangular form to indicate that adaptive strategies evolved positively over time to meet challenges and life phase changes. Spiraling arrows indicate a cyclical climb to new learning at stage of the life course. Of course people may have revisited adaptive techniques from an earlier time, but they also had to develop new sub-goals and ways of meeting those goals. Figure 4 is intended to demonstrate both regressive and progressive movement. The four cycles identified in this research are as follows.

1. Childhood and early adulthood:

A drive to independence as soon as possible after dealing with their respective reactions to impairment. During the first cycle, research participants were physically and emotionally challenged by surviving the onset of impairment or, in the case of children impaired from birth, the time of recognition of their difference from peers.

That didn't mean they accepted their bodily changes, it was simply the search for information and further treatment had ended for the time being. By now they understood their physical conditions were there for a long time and had adapted their self imagery and life goals. If assistive technology was available and useful to an active life style they used it. Coping strategies had been developed which included setting main social goals and physical sub-goals.

2. Adulthood:

Achievement of valued social roles. At this stage of impairment, the participants had to work on adaptive strategies which would enable them to meet their major roles. Respondents usually had the same overall social goals as non-impaired peers; gaining financial support, finding a partner, owning a home, finding and keeping employment, participation in recreation and taking on parenting roles. Education and employment, paid or voluntary, was crucial to informants having a positive social role.

Adaptive strategies were used to minimise the perception of one's impairment by non-disabled peers and those who may have held some authority in the lives of people with disabilities. Participants believed scrutiny of real or assumed weaknesses, by significant others such as school principals or employers, might lead to discriminatory behaviour. Participants set about busy lives as if activity alone could diminish perception of their impairments by non-disabled others. Strategies to enable role maintenance were developed so participants could achieve their goals and sub-goals without attracting too much unwelcome attention to their impairments. Significantly, during the research process, participants still described themselves in terms of roles and dominant activities. They avoided the term 'disabled.'

Participants met their role obligations, such as working in a building without a lift, even though it might entail walking up and downstairs with calipers and crutches. They exercised strong self control which in turn involved risky dissociative techniques such as compartmentalisation and suppression to enable performance of physically onerous tasks. These techniques assisted participants to distance themselves from pain, fatigue and exhaustion. In the long run dissociative techniques became maladaptive as people pushed themselves to the end of their physical and emotional reserves. By the end of this cycle participants had demonstrated success in achieving their broad goals.

Table 1.
Summary of adaptive strategies used to meet challenges within cycles.

Cycles	Impairment stage	Social context	Social challenge	Emotional reaction to recognition of impairment	Adaptive strategies
Cycle One. Childhood and early adulthood: drive to independence after Impairment.	Onset or recognition of impairment.	1920's – 1950's pre and post World Wars 1 & 2 veteran rehabilitation and general infrastructure development. Immigration promoted to enable economy building. Polio epidemics.	Eugenics theories. Institutionalisation. Poverty caused by difficulty in obtaining education and employment for people with disabilities.	Anger. Depression. Resignation.	Strive to survive, and formation of physical goals. Search for a cure and information about the impairment. Use of family support. Search for information and education Search for resources. Definition of desirable social roles and associated goals.
Cycle Two. Adulthood: achievement of valued social roles.	Maximum use made of available physical and psychological abilities.	Mid 1950's to 1980. Cold war and nuclear threats involving USSR, America and allied nations' economies. Immigration encouraged. Rights based legislation for example the Racial Discrimination Act 1975.	Civil rights discourse not fully extended to people with disabilities.	Anger at perceived discrimination. Anxiety about possible reactions by other people to perceived impairment. Pride at attaining roles and many goals.	Minimisation of impairments when facing relevant social systems such as employment. Strong self-control of impairment effects so as to portray, as far as possible, normal functional abilities. Dissociation from physical difficulties. Achievement of some social roles.

Cycles	Impairment stage	Social context	Social challenge	Emotional reaction to recognition of impairment	Adaptive strategies
Cycle Three. Middle Age: maintenance of roles while experiencing some impairment progression	Physical stressors perceived, secondary health conditions diagnosed and decline of physical function acknowledged. Growth of intergenerational responsibilities for partners, children and parents.	1981-1999 International Year of Disabled Persons 1981. Move from Welfare based legislation: Disability Services Act 1986, Superannuation Guarantee Act 1992, to the Sex Discrimination Act 1984, and Disability Discrimination Act 1992.	Citizen controlled systemic disability advocacy organisations struggled for funding to pursue equality of opportunities. Ageing of the Australian population was perceived by governments.	Satisfaction and pride about goal achievements. Anxiety about some new physical symptoms. Acknowledgment of positive aspects of identity as people with disabilities.	Seeking advice on the maintenance of health and management of impairment changes. Maintenance of roles commensurate with social maturity. Advocacy for equality of opportunity for oneself and, for some, advocacy for others. Growing use of assistive technology.
Cycle Four. Ageing: maintaining an identity as a person with disability while dealing with new and increased impairment.	Further growth of intergenerational responsibilities. Awareness of impairment progression as well as age related health conditions	2000 - > Conservative government budgets were concerned with projections of an ageing population, welfare reform, terrorism and defence pacts with international allies.	Ageing of families and friends. Partial cost shifting of facility or community based care, from government to the end user. People with disabilities without financial resources from superannuation less able to exercise choice when accessing services or purchasing technology.	Pride in the growth of legislation and services brought by advocacy. Confusion about the causal factors of physical decline. Fear of possible dependence. Fear and anxiety about possible implications of engaging with aged care systems.	Extended use of technology. Search for peer support and information when health professional advice is scarce or inadequate. Enjoyment of mature age social roles. Time made available for enrichment of life by reflection, recreation and relaxation.

3. Middle age:

Maintenance of roles while experiencing some impairment progression.

The third cycle occurred when participants were confronted with increased or additional impairments, at a time when they were putting maximum effort into work, family, further education and social activities. Impairment progression was beginning to affect all respondents and participants experienced some loss of their functional abilities at a time when they were fully engaged in the consequences of role achievement. Impairment progression was unexpected. There were few ageing role models of people with long-term physical impairments at the time participants were undergoing treatment or rehabilitation. Informants thought that as they regained functional ability post-impairment, that ability would last a lifetime.

In maturity participants coped with changes forced by secondary impairments or impairment progression by learning new skills and modifying or setting new personal goals. New adaptive strategies were developed as people matured. When participants noted deterioration in their physical function, they adapted by seeking advice on managing their health concerns. This is a change from earlier in their lives when participants or family members sought curative advice. Now they sought information on maintenance and management of their conditions. Significant problems occurred when informants found very few sources of informed advice on managing impairments into late middle age or acquired health issues.

While in this cycle participants were more comfortable with perception of their disabled identity by others. They were proud of what they had achieved; fulfilling lives despite impairments and disabilities. Although some participants may not have used the label of 'disability' to describe their relationship with their environments, they didn't try as hard to hide their impairments from others. They used assistive technology with less need to reduce the impact of mobility aids in the eyes of others. They used some of their expert knowledge to teach non-disabled people about specific and generic disability issues. Most informants reached out to others who were also struggling with some physical or learning difficulty. Most participants became role models, teachers and advocates to assist others to gain self-management, independence, and a sense of self worth.

4. Ageing:

Maintaining an identity as a person with disability while dealing with new and increased impairment.

The fourth cycle is unfinished for most participants who have survived into the present. Participants were different ages when they joined the study and during this last cycle, starting from 2000, participants respectively aged into their fifth, sixth, seventh and eighth decades. One participant died at the age of 81 after the study was completed. This cycle was one of development of new social tasks and responsibilities as respondents moved into inter-generational roles as grandparents, carers of ageing relatives, and advocates for other people. The social context became increasingly more complicated particularly by economic uncertainty. Participants experienced ageing both vicariously and directly by having to adapt to physical changes acquired during their own ageing processes.

The impairment stage during the fourth cycle was characterised by adverse physical changes requiring further adaptation. All informants found they were getting weaker, or had less energy, or suffered joint and bone pain or had less coordination, less ability to balance, or had a combination of these symptoms. Some had arthritic symptoms or osteoporosis, both of which may be related to impairments, or acquired through ageing processes. Some had developed disorders apparently unrelated to their impairments. These health conditions included cardiovascular disease and diabetes. Most reported episodes of unusually severe fatigue which caused further functional limitations. It was highly significant that participants were unable to distinguish whether their current health concerns and functional changes originated from impairment progression, or from changes caused by age acquired impairments.

Adaptive strategies used by participants brought mixed results. Instead of minimising or hiding the true level of their impairments, as they had done in the past, they used assistive technology and some domiciliary services. Technology to assist mobility impairment and Home and Community Care programs had become widely accepted by people with age related impairments. These services were designed to help people age in place.

Significantly, participants wanted to be differentiated from ageing peers in certain important ways. They did not want to be identified just as part of a chronological cohort. Rather than being submerged within the ranks of the ageing, they wanted to be distinguished as having managed a long-term physical impairment throughout their life course. They identified themselves as impaired by a specific non-age related diagnosis. This was a pragmatic adaptation as all had developed great expertise in managing their respective impairments.

Participants viewed the aged care system, which they experienced through interaction with their own parents and relatives, as large and impersonal. They avoided all but the most peripheral contact. Informants sought help from aged care programs only for funding mobility aids and home alteration. No respondent remembered being assessed by an aged care health professional except for the necessity of being 'assessed' before enrolling in home help programs or gaining access to mobility aids. Participants did not believe aged care was able to recognise their hard won self control, specific needs and self management skills. They did not seek specialist geriatrician advice because they believed their physical impairment was most likely the primary factor causing functional decline.

Participants perceived their self knowledge and personal control threatened if they were to be 'managed' as aged and therefore subject to aged care models of assessment. Respondents were fearful their functional decline might lead to potential loss of physical independence. They adapted by reducing the fear of more physical dependence by planning ahead so essential activities could be maintained. A related fear was the loss of a partner and again participants had devised possible solutions by planning other ways of achieving goals. Their need for updated information, on management of impairments while ageing, was frustrated by the fact that medical and ancillary staff, formerly involved in impairment treatment and maintenance, had largely retired or died. Some informants had sought medical and ancillary professional help for symptom management, such as neck pain, from surgeons, neurologists, complementary medicine and the very few medically auspiced impairment specific services. All participants sought advice and support from local doctors but found they were in a teaching role rather than being advised as a patient. A collaborative relationship between doctor and patient was valued but uncommon.

A strategy remembered from the past and used again was to seek peer knowledge. Peer support and information often became important when no expert advice was available. Most of the respondents subscribed to impairment and disability related newsletters which provided peer advice.

Dissociative techniques were not used to the same extent as earlier in life. They acknowledged their achievements in earlier life phases. All adapted by the investment of energy into supportive networks. Just as they had received family support in the past, they returned support to ageing family members, friends and acquaintances.

During this cycle participants were concerned with enriching their lives. They pursued interests in voluntary work, study, religion and relaxation. After coping with the deaths of friends and family members, most participants had thought about their eventual deaths and had anticipated what that would mean. All were primarily concerned with maintaining their social roles within their families and friendship circles until life's end.

Policy and Practical Implications

This present study has demonstrated some significant findings about the multiple facets of the experience of people ageing with long-term physical impairments. Arguably the most important finding is the need for enhanced self-management by people ageing with long-term physical impairments. Recognition of the expertise of people with disabilities, in managing primary impairments, must include understanding of their adaptive strategies. It is essential to involve such expertise to inform positive ageing strategies and health promotion. The strength of their self-control means information about ageing must be relevant and appropriate to each specific impairment and individual life goals. Broad non-tailored advice may well be seen as irrelevant, insensitive, and of no use. Professional practitioners working in the fields of disability, aged care and health promotion need to develop their discipline's approach to positive ageing of people with disabilities. People ageing with long-term physical impairments maintain their life goals, the achievement of which ought to be the focus of supportive practitioners and services. There remains a need to coordinate impairment specific services and those from the aged care sector, to develop an active interface between their knowledge and skills, to support the need for positive ageing of people with disabilities.

Recommendations

A. There remains a need to develop an active interface between the knowledge and skills of both the disability and aged care sectors , to support positive ageing of people with impairments.

B. We all bear some responsibility to assist people with impairments and their families in other cultural regions, to achieve their potential.

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