AGEING WITH LIFELONG DISABILITY
Individual Meanings and Experiences Over Time

Lieke van Heumen

Introduction
Ageing has increasingly been recognised as a lifelong process that occurs from birth through death (Elder Jr., Kirkpatrick Johnson, & Crosnoe, 2003). The life course perspective has therefore emerged as a key area of scholarship for understanding ageing (Dannefer, 2011; Elder Jr. et al., 2003). In addition, scholars acknowledge that an understanding of how life is experienced and interpreted by individuals is crucial to comprehending what it means to grow old (Schroots & Birren, 2001). These perspectives have methodological implications (Alkema & Alley, 2006; Jamieson, 2002; McAdams, 2001; Victor, Westerhof, & Bond, 2007) and have led to a vast body of theory and research revolving around individual narratives and life stories (McAdams, 2001) often referred to as narrative gerontology. Narrative gerontology uses the metaphor of life as story. This field of study aims to improve understandings of ageing by exploring the stories older people use to express their experiences (McAdams, 2001). Narrative gerontology explores the various ways in which stories operate in our lives, as well as how we ourselves function as stories. Non-gerontologists have contributed to the development of narrative gerontology, particularly disability scholars (Bornat, 2002).

There are at least two purposes in exploring life stories, to advance our knowledge and to improve lives (Schroots & Birren, 2001). With more knowledge about the life experiences of older adults, their current needs can be better understood. This holds important value for the population ageing with lifelong disability. It is the first time in history that many individuals with lifelong disabilities are living into old age (Mosqueda, 2004). Therefore, those who recently aged into older adulthood are the first generation of this population. This means limited knowledge is available about how they age (Kemp & Mosqueda, 2004). This chapter will outline the life course perspective and life story research and explore their application to the experiences of individuals who are ageing with lifelong disability. Additionally, contemporary understandings of individual meanings and experiences with disability over time will be discussed.

Life Course Perspective
Knowledge of the lifelong context in which individuals develop is needed to understand ageing and what it means for individuals to grow old (Cavanaugh, 1999; Elder Jr. et al., 2003). The life course perspective recognises that ageing is a lifelong process that occurs from birth through death. Individuals shape their own life course with their choices and actions. Life courses are also influenced by the opportunities and limitations individuals experience due to their unique historical and social circumstances.
The individual’s place in history operates in the shaping of that person’s life (Elder Jr. et al., 2003). The life course perspective also acknowledges that circumstances, events, and behaviour earlier in life (and prenatally) impact development as people age (Elder Jr. et al., 2003). The life course of individuals is shaped by cohort-historical factors (Elder Jr. et al., 2003; Marshall, 1996; Passuth & Bengtson, 1988). These are events or circumstances that many people in the same culture experience at the same time in their lives. This can provide them with a unique generational identity (Cavanaugh, 1999). The life course perspective also proposes that individual consequences of life transitions, events, and behavioural patterns differ based on their timing in the person’s life (Cavanaugh, 1999; Elder Jr. et al., 2003). Individuals from the same cohort can age in different ways if they have different experiences at different times in their lives and follow different pathways as a consequence (Elder, 2001). For example, individuals born during the 1920s in Europe had different exposure to WWII than their slightly younger siblings, who were too young to actively remember the difficult circumstances. Additionally, the war might have delayed the older siblings’ education and start of their working and family lives, altering the course of their lives.

Finally, people live their lives interdependently in networks of shared relationships. The life course perspective proposes that individual lives and experiences need to be interpreted with consideration of the individual’s significant relationships. Individuals can be impacted by large social changes and the influence of these on other people in their lives (Elder Jr. et al., 2003). For example, economic hardship during the U.S. farm crisis in the 1980s in the state of Iowa caused depression among parents. This in turn impacted child development in negative ways (Conger & Elder Jr., 1994).

**Life Course Perspective on Ageing with Lifelong Disability**

Little is known about what it is like to grow older with a lifelong disability, and what it is like to live with a disability over many years. Most research on ageing has addressed impairments associated with the ageing process rather than the impact of living a long life with disability or the experience of ageing with previous disabilities (Jeppsson Grassman, Holme, Taghizadeh Larsson, & Whitaker, 2012). There is also little research that has examined the experience of lifelong disability from a life course perspective (Jeppsson Grassman et al., 2012; Kelley-Moore, 2010; Parker Harris, Heller, & Schindler, 2012; Priestley, 2003; Yorkston, McMullan, Molton, & Jensen, 2010). The experiences of young adults, adults of middle age, and older adults tend to be considered independently, without acknowledgment of life course processes (Kelley-Moore, 2010).

There are several reasons that can explain the lack of research on disability that is informed by a life course perspective and addresses ageing issues. First, ageing with lifelong disability is a recent phenomenon. Due to improvements in social and health care, individuals with lifelong disabilities live into older age for the first time in history (Jeppsson Grassman et al., 2012; Mosqueda, 2004). Second, disability tends to be seen as a static condition (Kelley-Moore, 2010) that individuals learn to cope with once and for all using their available resources. There is a lack of recognition of the dynamic nature of disability and the lifelong process of adjustment to evolving needs and coping with secondary conditions (Jeppsson Grassman et al., 2012).

Applying the life course perspective to disability issues through various life stages and across generations is complex, but important to further our understanding of disability (Parker Harris et al., 2012). Exploring disabled lives and ageing experiences from a life course perspective creates a focus on the meaning of disability within life as a whole. It considers when individuals became disabled, how long they have lived with disability, how their disability experience impacted different stages of life, and how old they are at the moment of reflecting on their life with disability (Jeppsson Grassman et al., 2012). Disabling barriers impact people with disabilities of different generations in different ways through the life course. Therefore, there are differences in the life experiences of different age cohorts of persons with disabilities. Furthermore, a life course perspective to disability acknowledges that disability can be experienced differently in different stages of life (Irwin, 2001; Parker Harris et al., 2012).
Universal changes occur for all people as they age, but the rates and nature of change are different based on variability in individual circumstances across the lifespan (Heller & Marks, 2006; Kelley-Moore, 2010; Mosqueda, 2004). The resulting heterogeneity or diversity among older persons was recognised in gerontology as early as the 1970s. The occurrence of poverty and inequality in old age is another common theme in the field. These combined observations have led to the formulation of the cumulative advantage/disadvantage theory. This theory defines cumulative advantage/disadvantage as ‘the systemic tendency for inter-individual difference in a given characteristic (e.g., money, health, or status) with the passage of time’ (Dannefer, 2003, p. S327). Cumulative advantage/disadvantage has been operationalised not for individuals, but as ‘a property of populations or other collectivities (such as cohorts), for which an identifiable set of members can be ranked’ (Dannefer, 2003, p. S327).

Early challenging life experiences such as institutionalisation, lack of educational and social opportunities, and low income and poverty are prevalent in the lives of older people with lifelong disabilities. These experiences have formative and cumulative effects on their long-term economic, social, psychological, and physical well-being (Grant, 2005; O’Rand, 2009). Insight into such life experiences is needed to understand the lives of this population. A way to get access to these experiences is by retrieving the stories they share about their lives.

**Life Stories**

Storytelling is a fundamental aspect of being human. We ‘story’ our lives, who we are and the world around us. The stories produced by this process concern our lives as a whole – past, present, and future – that is, where we have come from, where we are now, and where we are going, providing them with a sense of unity and purpose (Basting, 2009; Gubrium, 2011; Kenyon & Randall, 2001; McAdams, 2001; Meininger, 2001). The life story consists of various scenes and scripts that make up someone’s identity (McAdams, 2001) and is ever changing.

Life stories connect and are created within the context of the larger story that persons live within. Lives are affected by the structure of society, such as social policies, power relations, and economic realities. It is important to realise that such structural dimensions can be crucial constraints, effectively stunting stories, silencing voices, and setting limits to persons’ sense of possibility. In the United States, disability policy promoting the rights of people with disabilities only started impacting the opportunities of people with disabilities from the 1970s, following fierce advocacy of the disability rights movement. The 1975 federal Education for all Handicapped Children Act (later renamed the Individuals with Disabilities Education Act) guaranteed the right of all children with disabilities to public education in the most integrated setting appropriate (Longmore, 2009). This meant that children with disabilities’ right to an education could no longer be dismissed.

Lives are also affected by sociocultural dimensions, namely the social meanings that are associated with ageing and the life course within a given cultural context (Gubrium, 2011; Kenyon & Randall, 2001; McAdams, 2001). Life stories reflect societal norms, values, and power relationships (McAdams, 2001). For example, people with disabilities encounter discriminatory attitudes on a daily basis as negative beliefs about what it means to live with disability are prevalent in dominant society (Fisher & Purcal, 2017).

Additionally, lives are fundamentally interpersonal. This means that stories exist to be told to others and are shaped by and entwined with the life stories of others. Finally, life stories also have an intrapersonal dimension as individuals create and discover meaning and coherence within each of them uniquely (Gubrium, 2011; Kenyon & Randall, 2001; McAdams, 2001; Meininger, 2005).

Life stories are of particular importance to older adults, as the longer life is, the more there is to be told. The importance of remembering and reviewing life to older adults has been widely acknowledged. Older adults’ subjective well-being is impacted not only by their present experiences but also by their past experiences, and their retrospective views on those experiences (Westerhof, Dittman-Kohli, & Thissen, 2001). Life review has been described as a means to age successfully (Butler, 1963) and
retrieving memories as an important activity in the last stages of life (Erikson, 1997). Talking about their life is a way for older people to make peace with themselves and their accomplishments. It can also provide them with insight into how they became the person they are today (van den Brandt-van Heek, 2011). In addition, older adults have wisdom to share with younger generations by telling their stories. As people grow older the issue of generativity, the need to guide younger people and support younger generations, may increasingly move to the front and centre of the life story (McAdams, 2001).

**Life Story Research with Adults with Lifelong Disability**

‘Life story research’ is the umbrella term used in this chapter to refer to work done with individuals to retrieve their life experiences. Life story research includes different methodological approaches that put individual’s lives and experiences and their context in the centre of investigation. Though these different approaches may have distinct characteristics and epistemological roots, they ultimately all aim to reveal lives or segments of lives of people. In-depth, qualitative interviews are the most common means by which researchers conduct life story research (Harrison, 2008). In addition to ‘life story research’, many different terms are used interchangeably and compete for attention within social sciences, such as ‘life history work’, ‘biography’, ‘oral history’, ‘reminiscence’, ‘narrative analysis’, and ‘life review’.

One way to distinguish these approaches is to determine how they relate to the subject and what the participation of the subject looks like (Bornat, 2002). Within oral history, life history work, reminiscence, and life review, the subject is an active participant in the research process. In contrast to oral history, life history work can also draw on other data sources, such as surveys or public data, to expand the analysis with the goal to understand social processes. Within reminiscence, retrieving memories aims to achieve improved well-being for the speaker or speakers involved. Life review tends to be conducted with an individual by a professional or practitioner who seeks to assist the individual to understand and reflect on their life as a whole, accepting it in all its aspects, as it has been lived. Life review serves more as an intervention than a research method. However, life history work and oral history often have strong life review aspects within them as well (Bornat, 2002).

Life story research has become a prevalent approach particularly in the intellectual disability field in Europe (e.g. Atkinson, Doeser, & Varga, 2000; Atkinson, Jackson, & Walmsley, 1997; Atkinson & Walmsley, 1999; Cadbury & Whitmore, 2010; Goodley, 1996; Gray, 1997; Hreinsdottir, Stefandsottir, Lewthwaite, Ledger, & Shuffeboatham, 2006; Husain, 1997; Mee, 2010; Roets, Goodley, & van Hove, 2007; Roets, Reinaart, & van Hove, 2008; Roets & Van Hove, 2003; Van Puyenbroeck & Maes, 2004). There are three approaches to work with the life experiences and stories of people with intellectual disabilities (Meininger, 2003, 2005; Van Puyenbroeck & Maes, 2004). In each of these, the process is more important than the product. First and foremost, the telling of the story should be meaningful to the individual (Van Puyenbroeck & Maes, 2008). The critical approach aims to recover the voices of people with intellectual disabilities. The facilitator serves as a critical educator who coaches persons with intellectual disabilities to claim authorship and ownership of their own life stories. This approach enhances individuals’ awareness of their past (Van Puyenbroeck & Maes, 2008). The person-centred approach refers to ‘life story work’. It aims to ‘retell, study and discuss life stories in contacts between persons with intellectual disabilities, their relatives and friends and caregivers’ (Meininger, 2005, p. 108). Life story work aims to inform individuals who provide everyday support to persons with an intellectual disability about their needs (Meininger, 2003, 2005; van den Brandt-van Heek, 2011) and, therefore, resembles strategies for person-centred planning (Aspinall, 2010; Van Puyenbroeck & Maes, 2008). The focus of this approach is not on empowerment, but rather on dialectical understanding and relational intimacy. One activity using this approach is creating a written record of a life story such as compiling a life book (Van Puyenbroeck & Maes, 2008). In the clinical approach, reminiscence is used as a diagnostic instrument and counselling method (Van Puyenbroeck & Maes, 2008).

For individuals with disabilities, creative and accessible methods should be used that do not rely on the individual’s ability to communicate verbally. Life stories can be captured using different media such
as a photo album, an audio account, a video report, or a ‘memory box’, which uses physical objects to represent memories. Multimedia life stories that use computer technology are another possibility to convey the life story. After working with a facilitator to retrieve and create the life story, persons with limited or no verbal communication can present it by pressing keys on the computer keyboard or another device. Music and sounds can be included in multimedia life stories to make it an animated and personal experience (Aspinall, 2010).

**Individual Meanings and Experiences of Disability over Time**

Life story research with adults ageing with lifelong disabilities provides insights into how they experience living with disability over time, as well as how they experience the ageing process. This section briefly discusses findings from a selection of studies in the small but growing body of work using life story research with older adults with lifelong disabilities.

Experiences with institutionalisation have been documented in life story research with older adults with intellectual disabilities. Cadbury and Whitmore (2010)’s project documented the long life of Patricia Collen in an institution, though she moved into her own home in old age. Mee (2010) facilitated individuals with intellectual disabilities sharing their oral histories with nursing students. The individuals with disabilities shared their negative experiences with being institutionalised.

A small number of studies have retrieved experiences of older adults with intellectual disabilities with ageing. In a study of adults with intellectual disabilities age 40 and older conducted in Ireland, most of the adults who were interviewed described their health as very good to excellent but they also expressed negative views of the consequences of ageing (Burke, McCarron, Carroll, McGlinchey, & McCallion, 2014). Brown and Gill (2009) conducted a participatory study with older women with intellectual disabilities. They found that these women experienced getting older in a mostly negative manner. They thought of ageing as a physical process and considered getting ill and dying as part of ageing. The women also experienced the loss of loved ones, such as parents, friends, or siblings. Some women experienced positive aspects of ageing, such as ‘getting discounts’ and believed that older people ‘deserve more respect’. A study conducted with older women with intellectual disabilities in Israel found that these women desired to be active and were reluctant to retire. Furthermore, they also associated ageing with physical deterioration and decline (David, Duvdevani, & Doron, 2015). In their study in Sweden, Kahlin, Kjellberg, Nord, and Hagberg (2015) also found that older adults with intellectual disabilities characterise ageing as a process of bodily change.

Little is known about the lives of older adults who have serious chronic mental illness. Nearly absent from the literature is research reporting on the perspectives of these individuals on their life experiences. A small life story-oriented interview study by Bülow and Svensson (2013), with seven adults aged from 60 to 72 with long-term mental illness, found their reflections lacked positive evaluation of their early stages of life. Memories of abuse or painful events were rampant. Similarly, positive evaluations of work and professional experiences were lacking. Study participants did not describe employment as important components of their life stories. The researchers remarked that the life stories of adults without disabilities tend to be structured in stages or chapters delineating distinct phases in the life course such as childhood, school, marriage and family, work life, retirement, and present life as an old person. In the life stories of the adults with mental illness in this study, this type of clear structure of life course phases was vague or absent. Participants divided their lives in ‘before’ and ‘after’ according to events related to their mental illness, such as when they first experienced symptoms or were first hospitalised. The participants’ experiences with being ill permeated most of their life experiences. Experiences related to work and family life complemented their experiences with mental illness rather than the other way around. Within the context of long-term experiences with psychiatric care and other supports, participants felt it had been difficult to assert self-determination and control over their own lives. The authors of the study remarked that the illness experience overshadowed other concerns in old age. Participants carried the illness they had lived with for most of their lives into older adulthood and as a
result some of the challenging experiences of ageing experienced by others, such as shrinking autonomy were not as noticeable. Their illness did not change in a significant way when they became an older person. The participants shared experiences of loneliness. Finally, they shared concern about the future related to having to receive inpatient care as well as to the use of new medication with more challenging side effects.

Shibusawa and Padgett (2009) completed 44 life history interviews with 25 adults with mental illness in New York City aged from 40 to 62 who had also been homeless. Many of the participants spoke about their lives with a sense of loss and regret about their past. In reflecting on their lives, some participants felt they matured as they entered mid-life and later adulthood. Many had struggled with feelings of being out of sync with their peers without mental illness. Some considered this to be caused by the severe deprivation caused by homelessness and associated survival mechanisms. Others felt that their behaviour set them apart and caused others to worry about them. Additionally, participants experienced the negative impact of stigma, and awareness of their age sometimes increased these feelings. Voluntary or involuntary institutionalisation brought participants the benefit of being temporarily relieved from the deprivations and temptations of life on the street. Being jailed or hospitalised involuntarily was not viewed as desirable by the participants, though they did consider these stays as a time to evaluate their lives. Participants were very aware of high illness and death rates among homeless individuals and they suspected their own life spans were going to be shortened.

A series of studies by Jeppsson Grassman and colleagues (2012) with older adults with physical disabilities in Sweden demonstrated that despite disability policy reforms in their lifetimes, they experienced many challenges to full participation in society. Some respondents said that they felt less concerned about aspects of their lives and bodies compared to their younger years. For example, they were not as concerned with their appearance or what others thought of them. The authors observed that age was of secondary importance in the lived experiences of adults who lived a long life with disability. Many of the study participants expressed concern about their future, particularly the possibility of receiving enough assistance.

**Conclusion**

Future research should apply the life course perspective to the experiences of adults ageing with lifelong disabilities and needs to take into account the impact of early life experiences on long-term health and well-being. The perspectives of older adults with lifelong disabilities on their lives continue to be a rare topic of investigation. Their lived experiences and those aspects of their lives that bring happiness, joy, and meaning should be examined. Such knowledge is important in designing effective policies and supports to meet the needs of this population.

There is a need for more inclusive approaches to research with adults with disabilities to increase the relevance and quality of research (Walmsley & Johnson, 2003). In inclusive research, adults with disabilities serve as active partners and not only as respondents or subjects. Additionally, research needs to be more accessible to adults with disabilities. Research methods and procedures should fit the population to be studied, and not the other way around. This requires an investment and commitment on the part of researchers, and a dedication to flexible approaches that meet individual needs of research participants with disabilities.

The application of life story work in support practices for older adults with disabilities holds the promise of bringing a meaningful experience to this population. Yet, life story work is not yet widespread in systems of services and supports. As more people age with lifelong disability, the field needs to expand and apply new techniques and methods to promote this population’s well-being.
Ageing with Lifelong Disability

References


Ageing with Lifelong Disability


Suggested Readings


