

# A Life Course Perspective on Growing Older With Cerebral Palsy

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## Abstract

Despite most children with cerebral palsy (CP) now living within typical life spans, little is known about how the effects of CP unfold across the life course and impact participation in everyday life during adulthood. In this study, we explored the experiences of 38 adults growing older with CP. Data were gathered using semi-structured interviews focused on participants' engagement in activities in their community and analyzed using a life course perspective to deepen our understanding of the experiences of our participants. We found that individual agency, family and social contexts, as well as larger sociocultural contexts all shaped participants' experiences as they grew older. The findings highlight the usefulness of the life course perspective for understanding how the effects of a diagnosis of CP unfold over time. Further use of this perspective can better inform health care services to meet the needs of adults with CP aging with a lifelong disability.

## Keywords

cerebral palsy; neurology; neurological disorders; midlife; aging; qualitative descriptive; United States

## Introduction

Cerebral palsy (CP), a group of permanent disorders of the development of movement and posture that affects participation in activities, is one of the most common causes of lifelong physical disability attributed to nonprogressive disturbances in the developing fetal or infant brain (Rosenbaum et al., 2007). CP affects between 1.5 and 4 individuals per 1,000 births worldwide and is characterized by abnormal muscle tone and impaired control of movement and posture (Oskoui et al., 2013). As a result of improved medical care, most individuals with CP now live to within 5 years of a typical life span, depending on the severity of the disorder (Strauss et al., 2004). Stable incidence rates in combination with increased life spans underscore the growing need to understand how the effects of CP unfold at different ages and stages across the life course.

Despite this need, CP is often characterized as a disorder of childhood, with most research and health care services to date focused on meeting the needs of children and adolescents with CP, with much less attention given to adults (Bagatell et al., 2017; Haak et al., 2009; Moll & Cott, 2013). Examining how adults with CP experience and negotiate aging with a lifelong disability is especially important given recent research highlighting how CP presents different challenges in adulthood. While the

brain injury causing CP in childhood is considered nonprogressive, adults with CP experience changes in their ability to participate in daily activities as a result of increased spasticity, decreased mobility, and increased pain and fatigue (Haak et al., 2009).

Adults with CP report age-related physiological changes in their health earlier than adults without CP, often in their early 20s (Horsman et al., 2010; Mudge et al., 2016). Secondary health conditions such as pain, fatigue, musculoskeletal and joint problems all contribute to decreased participation in daily activities (Hilberink et al., 2017; Hirsh et al., 2010; Peterson et al., 2013; Strax et al., 2010; van der Slot et al., 2010). In addition, typical age-related conditions such as osteoarthritis and muscle atrophy (Cremer et al., 2017; van der Slot et al., 2013) further limit daily activities and restrict participation (Sheridan, 2009). Despite an increase in functional gains during childhood from intensive rehabilitation, adults with CP report losing these gains over

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time as a result of both aging with CP and aging in general (Moll & Cott, 2013).

Although the literature has shown that adults with CP experience early and accelerated changes in function, less is known about the impact of these changes on participation in everyday life during the stages of young and middle adulthood. In adulthood, participation includes work and employment, economic life, and community, social, and civic life (World Health Organization, 2002). Research, though minimal, suggests adults with CP experience restrictions to participation as they are less likely than nondisabled peers to be employed, live independently, pursue post-secondary education, engage in physical activity, or marry or live with a partner (Hirsh et al., 2010; Murphy et al., 2000; Nieuwenhuijsen et al., 2009; Thorpe, 2009; van der Slot et al., 2010). In addition, qualitative researchers have pointed out the need to know more about how participation is impacted by aging for individuals with CP, given gaps in the knowledge base of health care professionals that fall short of meeting the needs of adults aging with CP (King et al., 2000; Moll & Cott, 2013; Mudge et al., 2016).

The purpose of this article is to report our understanding of the experiences of adults with CP growing older with a lifelong disability in their communities. In our research, we explored how adults with CP experience aging and the impact of growing older with CP on participation in their everyday lives. To better understand and describe the experiences of our participants, the life course perspective was chosen as a theoretical lens given its holistic approach to understanding human lives and development in context. The life course perspective is an interdisciplinary theory originally developed by Glen Elder (1994) that focuses on understanding how sociocultural contexts shape human lives over time (Elder et al., 2015). Life events, transitions, and trajectories make up individual lives and are shaped by age-differentiated life stages (Elder, 1998). Each stage (e.g., childhood, adolescence, young adulthood, middle adulthood, and older adulthood) is characterized by different experiences, milestones, and roles within a given society (Hutchison, 2011). Compared with traditional views of growing older that often focus on negative changes and progressive loss, the life course perspective considers the study of aging as synonymous with the study of human development (Elder & Johnson, 2002). Growing older is viewed as a multidimensional, continuous, and lifelong process influenced by social and historical factors, as well as encompassing processes of growth and change that involve both losses and gains (Alwin, 2012; Crosnoe & Elder, 2002).

Five major principles characterize the life course perspective and for the purposes of this study, provide a foundation for understanding how the effects of CP unfold across the life course (Elder, 1998; Elder et al.,

2003, 2015). The first principle, *lifelong development*, states that human development and aging must be understood as processes that materialize over time. For adults with CP, each stage of life shapes subsequent stages, such that participation in everyday activities in adulthood is influenced by experiences from childhood and adolescence. Life experiences at each age and stage reverberate across the life course and shape later life. The second principle, *historical time and place*, states that the life course of individuals is embedded in and shaped by the historical and geographical contexts experienced throughout life. For adults with CP, the historical and social contexts that constitute the backdrop for each stage of life, such as growing up after the passage of the Americans With Disabilities Act (ADA), have a strong impact on their life experiences.

The third principle, *timing in lives*, states that the developmental impact of a succession of life transitions or events is contingent on when these transitional events occur in a person's life trajectory. For example, receiving intensive rehabilitative therapy during childhood focused on addressing physical impairments can have a profound impact on later-life outcomes for adults with CP (Moll & Cott, 2013). Principle four, *linked lives*, emphasizes that lives are lived interdependently, and social and historical influences are expressed through a network of shared relationships. Adults with CP may have spent more time with their parents than children developing typically and this embeddedness within particular social networks has an impact on their life course trajectories (Bagatell et al., 2017). The fifth principle, *human agency*, states that individuals construct their own life courses through the choices and actions they take within the opportunities and constraints of history. Adults with CP report a growing awareness of bodily changes as a result of increased spasticity, pain, and fatigue, and describe actively modifying their routines to ensure continued participation in meaningful activities (Mudge et al., 2016).

During the process of data analysis, the principles of the life course theory were applied to deepen our understanding of the experiences of the participants. Along with utilizing the five main principles, the life course perspective also served to attune us, as researchers, to the fact that our study entered into participants' lives "midstream" (Elder et al., 2015). For adults with CP, their experiences during adulthood have been shaped by earlier life events, development, and contexts. While there is certainly a need for research and clinical practice to move beyond a focus on physical limitations and consider the "whole person," the need also exists to consider the "whole life" of adults with CP in context. In this way, the life course perspective provides a more holistic understanding of the effects of CP as they unfold during and across different ages and stages of the life course.

## Method

This research study is part of a larger multimethod project that aimed to use a novel methodological approach to assess community integration for adults with CP (Chan et al., 2019). The qualitative descriptive data used in the larger study to explore the everyday experiences of adults with CP in the community are the focus of this discussion.

### Recruitment

Participants were recruited through university-based hospital rehabilitation clinics, information flyers posted in common areas of the clinic, or through study flyers and recruitment emails provided to pertinent disability organizations, campus disability services, and personal contacts. Adults (18–65 years old) diagnosed with spastic CP and Gross Motor Function Classification Scale–Extended and Revised (GMFCS-E&R) Levels I–III were recruited for the study. This age range was chosen in the United States, as 18 is considered the age of majority and 65 is considered retirement age. Additional inclusion criterion was the ability to reliably communicate in English either verbally or through the use of technology to participate in a 1-hour interview.

### Procedure

Participants first completed a questionnaire designed to provide demographic and health information. Semi-structured interviews were then completed to gather information about participation in daily and community activities. The interviewer asked all participants if their current housing felt like “home” and if there was anything that helped them live as independently as possible. At times, these questions elicited discussion related to past events in the individual’s history that laid a foundation for current behavior or function. Other key questions asked if there were any locations where they wished they spent more time, or activities they wished they were more involved in, and if they faced any barriers to participating in the community during the specific week. These questions sometimes prompted participants to share stories about recent changes in function, or discuss current functional or environmental limitations. Interviews averaged 60 minutes and were completed in a private office at the university. Data were collected between December 2015 and August 2018. Participants received \$50 for completion of the full study.

### Data Analysis

In this study, two methods of data analysis were applied in an iterative, sequential manner to the same data set

(Simons et al., 2008). First, the participants’ accounts were explored through a process of conventional content analysis (Hsieh & Shannon, 2005) to understand the experiences of community participation for adults with CP. This method was applied to the whole data set, but the authors felt this single form of analysis failed to capture the complexity of participants’ experiences. Therefore, the principles of the life course theory were explored to expand upon the findings from the conventional content analysis. These two methods of data analysis were applied such that the earlier findings were instrumental in the direction of the later round of analysis.

*Method of conventional content analysis.* All interviews were transcribed verbatim through a professional transcription service and coded using open coding methods. Coding for the full sample began inductively with authors each independently completing line-by-line coding of one shared and one unique transcript. Subsequently, the authors met to discuss codes. Coding included a combination of descriptive, in vivo, and process codes (Saldana, 2016a, 2016b). This collaborative process occurred four times prior to developing an initial codebook with codes grouped into categories and emerging themes. Transcripts were then independently re-coded. Meetings were held weekly to discuss the coding process and reflections on the codes and categories. As part of the analysis, a matrix display was created containing summary information of the participants (age, gender, education, employment status, GMFCS-E&R level), a descriptive summary profile, representative themes based on the established codebook, illustrative quotes, and other observations (Averill, 2002; A. Hamilton & Maitetta, 2017). After each meeting, each author was assigned new interviews to code until all 38 transcripts were analyzed. Very few new codes were added based on the latter half of the sample. Preliminary conventional content analysis (Hsieh & Shannon, 2005) of six cases early in the data collection process highlighted transition issues, family support, and physical changes as well as accessibility and attitudinal barriers affecting participation. This initial exploration of the six cases served as a starting point for further analysis. Sharing findings from the coding process often confirmed and expanded some of the previously identified experiences from the six cases, but also noted differences in descriptions and experiences based on participant age and life stage, prompting the application of life course theory.

*Directed content analysis: Applying the life course theory principles.* The life course theory was familiar to Amanda Carroll given its use in her dissertation work. As analysis progressed, the relevance of this theory to the emerging findings was discussed during a collaborative meeting. Therefore, we decided to use a directed content analysis

process (Hsieh & Shannon, 2005) and apply the life course theory principles in a second round of analysis to gain a deeper understanding of participants' experiences. First, similarities and differences in the representative themes derived from the conventional content analysis were examined within the context of participant demographic information. This information was displayed in the matrix and facilitated connections in reoccurring themes of life span transitions and parental expectations related to age, education, and employment status of participants, while also offering the opportunity to revisit prior findings within the context of the life course perspective. The life course principles were then used as categories to organize the data. Additional codes emerged through inductive analysis as all transcripts were then re-analyzed and the matrix updated to identify any life course principle(s) represented, and how it specifically applied to the adults with CP in this sample. This process led to establishment of broader themes from the data and was a continuation of the bottom-up process in which the themes fit within each of the life course principles as a main category. All authors reviewed the identified themes and associated raw data for confirmation.

### **Research Ethics, Rigor, and Researcher Positionality**

We gained approval from our local university institutional review board to undertake this study. Prospective participants were given written information about the study, including the right to confidentiality, anonymity, and the right to withdraw at any point. Full informed consent was gained from each participant in person. All participants provided written consent to have their interviews audio-recorded. Confidentiality was maintained by assigning pseudonyms to all interview participants and data were stored and accessed through the affiliated university's secure server.

While a range of strategies are available to researchers using a qualitative descriptive approach given its broad nature (Stanley, 2015), we used two main strategies to achieve rigor in this study: investigator triangulation and intercoder reliability. We triangulated data across researchers to develop emerging categories and themes. Interview transcripts were read independently and emerging findings were discussed and clarified at team meetings. In addition, research team meeting minutes were recorded. The minutes included notes about the progression of methodological and analytical decisions made as analysis progressed, thus creating an audit trail. Member checking was not used in this study given the time intensive nature of this strategy for participants (J. B. Hamilton, 2020) and recent critiques of this strategy (Morse, 2015).

As part of researcher reflexivity, a relevant aspect of our collective background is that we are all health care professionals with previous clinical and research experience working with adults with disabilities. The authors' backgrounds are from allied health sciences and we acknowledge this background has influenced our analysis and interpretation of the data. While our clinical experience was not mentioned to participants, it may have contributed to building rapport during interviews.

## **Results**

### **Participants**

Thirty-eight adults with CP participated in the study. The majority of the participants were female (63.2%), driving independently (63.2%), and unemployed (57.9%). The average age was 31.42 years (see Supplemental File for detailed description of participant demographics).

### **Life Course Principles and Corresponding Themes**

The findings are organized into themes corresponding to the five principles of the life course perspective following the precedent of other qualitative research utilizing this paradigm (Harrison et al., 2008). We first describe each principle and then present the themes that emerged describing participants' experiences of growing older with CP. Quotes from participants, which have been minimally edited for clarity, are used as exemplars to illustrate the themes confirmed across the data set.

**Life span development.** The first principle of life span development recognizes that development and aging are lifelong processes (Elder et al., 2015). This principle calls attention to the connections between later-life adaptation and experiences during earlier developmental years. The transactional nature of the life course, with each stage shaping past, present, and future stages, emerged in the experiences of the adults with CP. Two main themes captured this principle: the influence of parental expectations during childhood and adolescence on present experiences, and apprehensiveness and anticipation regarding growing older shaping present experiences.

**Parental expectations.** Participants' experiences during childhood and adolescence had lasting effects on their participation in everyday life during adulthood. A number of participants commented on the impact of parental expectations during the earlier stages of the life course on their development and independence as a person. Many participants reported that parents emphasized independence by encouraging participants to do more for themselves in

an effort to prepare them for the future. For instance, one of the youngest participants in the study noted the influence of changes in her parents' expectations during her senior year of high school. She recalled prior to leaving home for college, "My parents sort of started to make me do a lot more on my own. Their favorite line was 'we're not moving into your dorm with you, you have to figure it out.'" She credited this push to figure things out for herself as a main reason why she was able to successfully live by herself in a college dorm.

Other participants described how during childhood their parents insisted they would not provide them with accommodations due to their disability. Participants attributed this as instilling in them the ability to problem-solve and adapt to challenging situations throughout their life. For example, one participant reflected that her parents explained to her at an early age that, being the youngest of five children, they could not spoil her or treat her differently given the busyness of their large family. She recalled how her parents pushed her to fit in with her peers and do things around the house just like her siblings:

There wasn't a lot of accommodations going on, I lived in an old Victorian house, if I had to do stairs for surgeries and stuff like that, my dad was insistent, she can't go home unless she can get up and down stairs.

During middle adulthood, she positively attributed her view of herself as "very able-bodied" and her ability to "go with the flow" to the way she was raised by her parents.

*Apprehension of aging.* For others, the impact of future expectations regarding everyday life as older adults had a large impact on their current experiences. Participants in their 40s and 50s expressed apprehension and anticipation regarding what to expect in older adulthood. One participant described how he spent time thinking about how he was going to navigate the stairs and steps in his apartment as he got older given how increased spasticity and pain were already limiting his mobility. He called attention to the lack of knowledge regarding how bodily changes will play out stating that "we don't know" what happens to people with CP as they age. He described, "That's one of the reasons I'm happy to do this study is 'cause I've heard people before [say] 'hey what happens to me when I get to 70?'"

*Historical time and place.* This principle highlights that the life course of individuals is embedded in and shaped by the historical times and places they experience over their lifetime (Elder, 1998). Opportunities and life paths of individuals and cohorts are influenced by historical events and trends including institutional policies, laws, and technological developments.

*ADA and (in) accessibility.* Many of the participants, especially the younger participants, grew up following the rise of the self-advocacy movement and the passage of the ADA (Pub. L. No. 101-336, 104 Stat. 328). Therefore, for these participants, disability was not viewed as something residing in oneself but rather a limitation imposed by the environment. For example, one participant suggested that being a college student is challenging because of the inaccessibility of the campus and others' attitudes, not because of his CP itself.

Though participants in this study had greater access to the community than individuals with CP who grew up before the passage of the ADA, most described situations where access was still restricted. One participant described having to negotiate accessibility at work, "They organized a lunch at work and the place was up stairs. And there was no other access." Stories of inaccessible restaurants, stores, sports events, apartments and dorm rooms, and limited transportation were frequently shared without prompting.

*Advances in technology.* A powerful historical change has been advances in technology that have occurred over the past two decades that enable participants to participate more fully in community life. For example, many of the participants were not able to drive and thus relied on other available transportation options. While some participants used paratransit, public transportation designed specifically for people with disabilities mandated by the ADA, most found this service unreliable and frustrating. In fact, many told stories of being stranded or having to wait hours for the service. However, newer modes of transportation have provided an alternative for some participants who live in less rural areas and have financial resources. For example, one participant, a graduate student, noted, "I kind of don't know what I would be able to do if Uber didn't exist. Uber is kind of like how I maintain sanity and I'm able to get out of my house." In addition, on-line shopping for clothes and groceries enabled participants to complete these activities without having to tax themselves physically. Another participant who experienced high levels of pain and fatigue described: "that [using grocery store pick up service] really saves me an hour's worth of pain . . . I would pay a whole lot more if I get more hours in the week without pain."

Not all historical changes, however, have been positive. For many participants, changes in health care have resulted in having to navigate many systems and encounter more restrictions on therapy services and coverage for durable medical equipment. For example, a participant recounted her frustration with getting a new scooter; the insurance company would only approve a wheelchair and not a scooter, which she described as much more useful in the community.

*Linked lives.* The principle of linked lives suggests that people are connected to others—that lives are lived interdependently. Family ties and social relationships can influence how individuals interpret life events. These linkages can facilitate or inhibit opportunities that enhance quality of life (Elder, 1998). The principle of linked lives was reflected in the data in two main ways: (a) interdependence with others and (b) family, friends, and work colleagues as social supports.

*Interdependence.* As participants reflected on what helped them to be independent in their lives, family beliefs and experiences were frequently mentioned. Many participants noted that their parents treated them “like everyone else” and expected them to participate fully in family and community life. Others noted that parents encouraged them to get involved:

My whole life, my family has always been saying like, get involved in you know—in school and whatever you’re doing . . . my family is really hands on and that has made a huge difference in my life.

Conversely, some participants reflected on how parental expectations and beliefs actually limited their participation and independence. For example, one described, “I grew up in a house where I wasn’t allowed to use the stove.”

In adulthood, many of the participants continued to live with family or see them frequently. Many participants identified family as a major source of support—financial, social, emotional, and logistical support, such as providing transportation. One participant, a PhD student, responded immediately to our question about who provides social support:

He’s [my husband] just like everything from physical stuff, when my CP is flaring up to like when I’m crying about the PhD and I think I’m never going to finish. . . He helps me with everything, like if I can’t open cans or chop up vegetables.

Interestingly, many of the participants described the give and take in their relationships—the interdependence rather than dependence. For example, one participant described how after becoming unemployed she moved back home with her mother. While she was benefiting financially from this arrangement, her mother also benefited by having her daughter at home to assist with household chores and run errands. They also supported each other emotionally as they both were looking for jobs: “My mom is very supportive and helping me find a job. We send each other jobs all the time.”

*Social supports.* For some participants, their lives were linked in powerful ways to friends—friends with whom

participants felt that they could be themselves, friends who accepted but did not dwell on their physical limitations. For example, a participant shared that his life is closely linked with friends from his time as an undergraduate. In fact, he moved to another state for graduate school with his friends. Another participant described how a close friend offered her a job to help her out during a tough time, “When I lost job, she’s [friend] kind of like, hey, I need a little help, you know, getting organized . . . so working there has been a good fit.” Not all participants, however, were able to identify friends as social supports. Many experienced loneliness and isolation. This was especially true for some of the single, male, middle-aged participants who worked full-time. Aside from spending time with co-workers at work and having occasional contact with family who lived out of the area, these participants struggled to experience their lives as linked.

*Timing.* The fourth principle of timing notes that “the developmental antecedents and consequences of life transitions, events, and behavioral patterns vary according to their timing in a person’s life” (Elder et al., 2003, p. 12). The timing of transitions and milestones emerged as significant in the experiences of adults with CP, centered on two main themes: timing of the transition to adulthood as young adults, and an accelerated transition to older adulthood as body changes and pain necessitated limiting activities at an earlier age.

*Delayed transitions.* For the transition to adulthood, participants who were young adults often described this process as being delayed or still in process related to living on their own, being under or unemployed, and having difficulty finding friends after high school once the scaffolding of services, supports, and daily peer contacts were removed. “I am still transitioning,” noted one participant, a college student, who stated he is still trying to find his place. He reported his friends from high school used to be his biggest form of social support, but now it is his parents. Another participant who was volunteering once a week and searching for employment and a friend group since high school reported a similar experience. He enjoyed going to the local library once a month for teen night, but at 21 he was soon transitioning out of the one place he stated he felt he belonged. The desire for employment and associated independence of living apart from parents was most often expressed by the younger cohort and is often part of the idea of emerging adulthood, but one participant, who was 38 years old, shared a similar experience. He had always lived with his parents, in the same community where he grew up, and was trying to start a self-employment venture but seemed to express frustration with missing the turning point or transition in his life, wishing he had more to do to be able to get out

of his home town:

Everybody knows me . . . but I have no social support . . . I want to make more money. And, [I'm] trying to get the damn dumb (self-employment) thing started. That's the number one goal . . . because it would give me more stuff to do . . . I would get to travel more often and not have to stay around this little town.

*Accelerated aging.* For others, timing and transition were expressed as an advanced transition, where health issues accelerated limiting activities and function early in life. This was noted by all but one participant aged 40 to 50 years old. He highlighted this, stating,

Disability crept up slowly over time . . . [I am] learning to think of myself as disabled or slowed down, particularly when it comes to work, saying, 'I can't do this right now,' has been a real blow to my ego and uh, a real—just a real downer.

Others reported pain limiting activities during the day, needing to build in days of rest and recovery during the week, and needing to plan ahead for the future based on current bodily changes. However, younger participants also described limitations due to pain affecting their lives even earlier on, as one participant described:

I'm having this nerve pain in my foot . . . I've had it for about 2 months. And that is making it very hard to walk more than, like, 15 minutes at a time. Or stand . . . this has been the most recent and most painful, like sad, effect of how I walk. I'm in the process of figuring it out, I just haven't gotten there.

Other younger participants described limiting activities such as preferring to stay in the car when going out in the community with others or not accompanying friends on shopping trips due to fatigue.

*Human agency.* The fifth principle of human agency calls attention to how individuals exercise agency in their lives “through the choices and actions they make within the opportunities and constraints of history and social circumstances” (Elder et al., 2015, p. 29). For the adults with CP, cultivating their sense of agency in the face of constrained circumstances emerged as a significant theme reflective of their experiences. Participants across the age range described how they negotiated the constraints of different social structures and norms in their everyday lives.

*Retaining choice and taking action.* Many noted instances of making choices or taking actions in the face of limited opportunities to participate and in response to decreased function and mobility. For example, one participant identified a number of accessibility and environmental barriers

that limited her participation in meaningful activities such as watching her nephews' soccer game. She described, “everywhere you go is not handicap accessible because we had to go down a hill to even get to the game . . . I felt like I was just sitting there.” These experiences with limited accessibility and decreased participation in meaningful activities in the community impacted her decision to become a homeowner and design an environment that facilitated her participation. In response to being asked to describe her current living situation, she noted,

Probably the most accessible place I've lived as far as accessibility. . . I did a lot of things myself. I had all the ramps built, put on . . . one of the bathroom doors—had one of those little mini doors, really skinny doors so I had to get it widened out . . . I knew what I needed so I looked for that when I bought a house.

*Negotiating receiving help.* Many young adults in the study described their time in college as a context that pushed them to cultivate their own sense of agency. Through their college experiences, they reported gaining confidence in advocating for their own needs and asking for help when needed. In middle adulthood, participants described exercising agency in their everyday lives through their negotiation of bodily changes and functional decline. This theme resonated in the experiences of participants in their 40s and 50s as they described making choices and taking action in ways that allowed them a degree of control over challenging situations. One participant reported negotiating how he received help from others due to declines in his mobility and balance. He detailed how he was coming to terms with needing to ask for help due to decreased endurance and mobility, noting “the hardest thing for me to do was to learn to ask for help.” He described an increase in falls over the past year, but noted that when he does fall, he has a specific way he exerts agency when this happens:

I do normally stay on the ground 30 seconds and kind of take stock and let my body get over the shock of it and then I'll say, “ok honey.” My wife, she's usually with me, I say, “I just need to be here for a minute. Just let me climb up the side of the bed or whatever and we'll be fine.”

In this way, he actively re-established a sense of control and autonomy during a situation that otherwise threatened his sense of self.

## Discussion

In this article, the life course perspective was applied as a theoretical framework to better understand the experiences of 38 adults with CP as they navigated growing older with a lifelong disability. We explored how the

effects of CP unfolded across early and middle adulthood and the impact of growing older with CP on participation in everyday life. Through application of the life course principles, we were able to develop a multidimensional understanding of how participants' earlier life experiences set the stage and continued to shape their experiences in adulthood. The life course perspective also attuned us to continuities in the participants' lives, as well as the impact of the timing of life events and transitions. We found that the family context, social contexts of friends and the workplace, as well as larger societal and cultural contexts all shaped participants' experiences of growing older with CP.

An important advantage of the life course perspective is its focus on capturing how sociocultural contexts and social institutions play a large role in shaping human lives. Surprisingly few studies have applied the life course perspective to people with disabilities. Harrison (2003) and Harrison et al. (2008) used the life course perspective to understand the lives of women aging with childhood onset disabilities. Our findings support their conclusions that the life course perspective offers a useful way for researchers and clinicians to understand health outcomes for people with disabilities. The findings of our study are also consistent with other health-related literature highlighting the impact of macro level systems on the life course of individuals with CP. Moll and Cott (2013) found that within the context of the U.S. health care system, front loading of health care services during childhood and adolescence may put individuals with CP at a disadvantage as they grow older. Participants described that as children, health care services focused on "normalizing" their functional abilities, while as adults they were unable to maintain these functional gains. Participants in their study similarly confronted feelings of apprehension and frustration regarding what to expect as they grow older and lack of access to knowledge or health care services to meet their evolving needs as they aged. These sentiments were echoed in a study of adults with CP in New Zealand who also experienced a health care system focused on meeting their needs as children, but not as adults (Mudge et al., 2016).

In addition to larger health care systems, our findings demonstrated that changes in legislation and technology at the societal level also had, to some degree, an impact on the everyday experiences of adults growing older with CP. Changes in education policies in the United States, beginning in the 1970s, have enabled individuals with CP to be educated along with their nondisabled peers. In addition, the passage of the ADA in 1990 (Pub. L. No. 101-336, 104 Stat. 328), a civil rights law which prevents discrimination against individuals with disabilities in all areas of public life, including job settings, transportation, educational settings, and community spaces, has enabled individuals

with CP greater access to community life. Finally, the self-advocacy movement, which began in the 1970s and paralleled the civil rights movement, highlighted empowerment, equal opportunity, and self-determination. Despite these policy changes, participants continued to experience challenges accessing the community.

Along with highlighting the influence of history and larger sociocultural contexts on human lives, the life course perspective conversely attunes researchers to the role of human agency in shaping the life course. In contrast to more deterministic views of aging, the life course perspective's emphasis on agency provides a more nuanced understanding of how adults with CP actively navigate growing older with a lifelong disability. Findings of this study are consistent with other studies outside the United States showing that adults with CP exercise agency in the way they respond to physical and functional changes as they grow older. Palisano et al. (2020) found that young adults with CP in Canada developed a process of actively adapting to different contexts over time to participate in activities perceived as important to their health and well-being. Similarly, research in Norway and Canada has shown that adults with CP are proactive in promoting their health and well-being by employing strategies to cope with the impact of age-related changes on their daily life (Gjesdal et al., 2020; Horsman et al., 2010). Mudge et al. (2016) found that one coping strategy used by their participants in New Zealand was taking charge of needing help as they aged. The adults with CP in their study actively took charge of help from family members as well as professional help. They negotiated the terms of help received and cultivated assertiveness to maintain a sense of autonomy in the context of accelerated aging.

At the same time, application of the life course theory highlighted the importance of connection to others early in life, particularly family, and its influence of perceptions of self and capabilities in adulthood. The findings related to linked lives build on prior research with adolescents and young adults with CP. These individuals report that interdependence with others contributes to feelings of belonging and acceptance as an important, but largely overlooked, indicator of success in adulthood (King et al., 2000).

### *Limitations*

A primary limitation of the study is that the life course theory was not the guiding framework of the original study design. Interview questions were not designed to elicit discussion on the specific life course principles. Therefore, participants did not have the opportunity to share how these principles may directly apply to their life, and similarly, life experiences related to all of these principles were not shared by every participant. However, it is



notable that the life course principles emerged in the analysis of the data without a preconceived framework. Future research designed with these principles in mind can include questions that specifically address each of the life course principles for a more comprehensive inquiry and application of the theory for this population. The current findings provide a starting point for interview content and question prompts that may be relevant for adults with CP.

Additional limitations are that the majority of the sample consisted of individuals with mild mobility limitations (walking without assistance or with a cane or walker), and interview questions primarily sought information on engagement in activities in the community. The experiences of these participants as they relate to each of life course principles of agency, timing, linked lives, historical context, and life span development may be very different than those with more severe mobility limitations. Finally, it is important to acknowledge that this study took place in the United States, whose health care and educational systems and policies are unique.

### Implications for Practice and Research

For practitioners working with individuals with CP, it is important to be aware of and prepare individuals with CP for the potential physical and emotional changes they may experience as they grow older and the impact of these changes on their sense of identity. Practitioners should acknowledge linkages between historical epoch and opportunities as well as linkages between early life experiences and experiences in adulthood. Rather than focusing on remediation of physical limitations, practitioners should encourage self-determination and self-advocacy, and prioritize social connection along with independence. Incorporating questions into assessments to capture a life course perspective is warranted. Examples of questions include the following: What has helped you to engage in the things you need and want to do? How would you describe the expectations of family members and/or educators when you were growing up? How do you advocate for yourself? Who are your most important forms of social support? What changes have you noted in your physical abilities? What types of services, technologies, or accommodations do you use regularly?

Although the life course perspective provides a useful conceptual framework for research attending to the diversity and heterogeneity of life course trajectories, this strength may also be a challenge given the increasing complexity of societies and cultures around the world (Hutchison, 2011). The findings of our study, which took place in the United States, are consistent with results from other Western countries (Gjesdal et al., 2020; Horsman et al., 2010; King et al., 2000; Mudge et al., 2016; Palisano et al., 2020) suggesting that the life course

perspective may have broader applicability. Future research is warranted using cross-cultural applications of this perspective to better understand how adults with CP are aging with a disability across the globe.

### Conclusion

Using a life course perspective, the dynamic interrelationships between sociocultural contexts and individual lives can be studied in a way that captures how individuals exercise agency within structural systems. Importantly, this perspective can be used to illuminate the effects of CP as they unfold across the life course by considering trends and patterns across and between cohorts situated in historical time and place as well as the individual lived experience. This theoretical nimbleness is imperative to the study of adults with CP given that although individuals may share similar experiences, there is no one singular experience of growing older with CP. However, using the life course perspective, we found that individual agency, family and social contexts, as well as larger sociocultural contexts all shaped participants' experiences of growing older with CP. Further use of this perspective holds potential to better inform health care services to meet the needs of adults with CP aging with a lifelong disability.

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### Supplemental Material

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### References

- Alwin, D. F. (2012). Integrating varieties of life course concepts. *The Journals of Gerontology, Series B: Psychological Sciences & Social Sciences*, 67(2), 206–220. <https://doi.org/10.1093/geronb/gbr146>
- Americans With Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 328 (1990).

- Averill, J. B. (2002). Matrix analysis as a complementary analytic strategy in qualitative inquiry. *Qualitative Health Research, 12*(6), 855–866. <https://doi.org/10.1177/104973230201200611>
- Bagatell, N., Chan, D., Karrat Rauch, K., & Thorpe, D. (2017). “Thrust into adulthood”: Transition experiences of young adults with cerebral palsy. *Disability and Health Journal, 10*(1), 80–86. <https://doi.org/10.1016/j.dhjo.2016.09.008>
- Chan, D., Thorpe, D., Trost, S., Boyd, R., Faldowski, R., Barber, L., Levin, I., Carroll, A., & Bagatell, N. (2019). Novel approaches to measuring community integration in adults with cerebral palsy. *Disability & Rehabilitation, 64*, 1–12.
- Cremer, N., Hurvitz, E. A., & Peterson, M. D. (2017). Multimorbidity in middle-aged adults with cerebral palsy. *American Journal of Medicine, 130*, 744.e9–744.e15. <https://doi.org/10.1016/j.amjmed.2016.11.044>
- Crosnoe, R., & Elder, G. H. (2002). Successful adaptation in the later years: A life course approach to aging. *Social Psychology Quarterly, 65*, 309–328. <https://doi.org/10.2307/3090105>
- Elder, G. H. (1994). Time, human agency, and social change: Perspectives on the life course. *Social Psychology Quarterly, 57*, 4–15. <https://doi.org/10.2307/2786971>
- Elder, G. H. (1998). The life course as developmental theory. *Child Development, 69*(1), 1–12. <https://doi.org/10.1111/j.1467-8624.1998.tb06128.x>
- Elder, G. H., & Johnson, M. K. (2002). Educational pathways and work value trajectories. *Sociological Perspectives, 45*(2), 113–138. <https://doi.org/10.1525/sop.2002.45.2.113>
- Elder, G. H., Johnson, M. K., & Crosnoe, R. (2003). The emergence and development of life course theory. In J. T. Mortimer & M. J. Shanahan (Eds.), *Handbook of the life course* (pp. 3–19). Kluwer Academic/Plenum Publishers. [https://doi.org/10.1007/978-0-306-48247-2\\_1](https://doi.org/10.1007/978-0-306-48247-2_1)
- Elder, G. H., Shanahan, M. J., & Jennings, J. A. (2015). Human development in time and place. In M. H. Bornstein & T. Leventhal (Eds.), *Handbook of child psychology and developmental science* (pp. 1–49). John Wiley.
- Gjesdal, E. B., Jahnsen, R., Morgan, P., Opheim, A., & Mæland, S. (2020). Walking through life with cerebral palsy: Reflections on daily walking by adults with cerebral palsy. *International Journal of Qualitative Studies on Health and Well-Being, 15*(1), 1746577. <https://doi.org/10.1080/17482631.2020.1746577>
- Haak, P., Lenski, M., Hidecker, M. J. C., Li, M., & Paneth, N. (2009). Cerebral palsy and aging. *Developmental Medicine & Child Neurology, 51*(Suppl. 4), 16–23. <https://doi.org/10.1111/j.1469-8749.2009.03428.x>
- Hamilton, A., & Maietta, R. (2017, July). *Rapid turn-around qualitative research* [Paper presentation]. 14th Annual Qualitative Research Summer Intensive, ResearchTalk, Inc, Chapel Hill, NC, United States.
- Hamilton, J. B. (2020). Rigor in qualitative methods: An evaluation of strategies among underrepresented rural communities. *Qualitative Health Research, 30*, 196–204. <https://doi.org/10.1177/1049732319860267>
- Harrison, T. (2003). Women aging with childhood onset disability: A holistic approach using the life course paradigm. *Journal of Holistic Nursing, 21*(3), 242–259. <https://doi.org/10.1177/0898010103254917>
- Harrison, T., Angel, J., & Mann, A. (2008). Mexican American women aging with childhood-onset paralytic polio. *Qualitative Health Research, 18*(6), 767–774. <https://doi.org/10.1177/1049732308318751>
- Hilberink, S. R., van der Slot, W. M., & Klem, M. (2017). Health and participation problems in older adults with long-term disability. *Disability and Health Journal, 10*(2), 361–366. <https://doi.org/10.1016/j.dhjo.2016.12.004>
- Hirsh, A. T., Gallegos, J. C., Gertz, K. J., Engel, J. M., & Jensen, M. P. (2010). Symptom burden in individuals with cerebral palsy. *Journal of Rehabilitation Research and Development, 47*, 863–876. <https://doi.org/10.1682/JRRD.2010.03.0024>
- Horsman, M., Suto, M., Dudgeon, B., & Harris, S. R. (2010). Growing older with cerebral palsy: Insiders’ perspectives. *Pediatric Physical Therapy, 22*(3), 296–303. <https://doi.org/10.1097/PEP.0b013e3181eabc0f>
- Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*, 1277–1288. <https://doi.org/10.1177/1049732305276687>
- Hutchison, E. D. (2011). Life course theory. In R. J. Levesque (Ed.), *Encyclopedia of adolescence* (pp. 1586–1594). Springer.
- King, G. A., Cathers, T., Polgar, J. M., MacKinnon, E., & Havens, L. (2000). Success in life for older adolescents with cerebral palsy. *Qualitative Health Research, 10*, 734–749. <https://doi.org/10.1177/104973200129118796>
- Moll, L. R., & Cott, C. A. (2013). The paradox of normalization through rehabilitation: Growing up and growing older with cerebral palsy. *Disability and Rehabilitation, 35*(15), 1276–1283. <https://doi.org/10.3109/09638288.2012.726689>
- Morse, J. M. (2015). Critical analysis of strategies for determining rigor in qualitative inquiry. *Qualitative Health Research, 25*, 1212–1222. <https://doi.org/10.1177/1049732315588501>
- Mudge, S., Rosie, J., Stott, S., Taylor, D., Signal, N., & McPherson, K. (2016). Ageing with cerebral palsy; what are the health experiences of adults with cerebral palsy? A qualitative study. *BMJ Open, 6*(10), e012551. <https://doi.org/10.1136/bmjopen-2016-012551>
- Murphy, K. P., Molnar, G. E., & Lankasky, K. (2000). Employment and social issues in adults with cerebral palsy. *Archives of Physical Medicine and Rehabilitation, 81*(6), 807–811. [https://doi.org/10.1016/S0003-9993\(00\)90115-1](https://doi.org/10.1016/S0003-9993(00)90115-1)
- Nieuwenhuijsen, C., van der Slot, W., Beelen, A., Arendzen, J. H., Roebroek, M. E., Stam, H. J., & van den Berg-Emons, R. J. (2009). Inactive lifestyle in adults with bilateral spastic cerebral palsy. *Journal of Rehabilitation Medicine, 41*(5), 375–381. <https://doi.org/10.2340/16501977-0340>
- Oskoui, M., Coutinho, F., Dykeman, J., Jette, N., & Pringsheim, T. (2013). An update on the prevalence of cerebral palsy: A systematic review and meta-analysis. *Developmental Medicine & Child Neurology, 55*(6), 509–519. <https://doi.org/10.1111/dmcn.12080>
- Palisano, R. J., Di Rezze, B., Stewart, D., Freeman, M., Rosenbaum, P. L., Hlyva, O., Wolfe, L., & Gorter, J. W. (2020). Promoting capacities for future adult roles

- and healthy living using a lifecourse health development approach. *Disability & Rehabilitation*, 42, 2002–2011. <https://doi.org/10.1080/09638288.2018.1544670>
- Peterson, M. D., Gordon, P. M., & Hurvitz, E. A. (2013). Chronic disease risk among adults with cerebral palsy: The role of premature sarcopenia, obesity and sedentary behaviour. *Obesity Reviews: An Official Journal of the International Association for the Study of Obesity*, 14(2), 171–182. <https://doi.org/10.1111/j.1467-789X.2012.01052.x>
- Rosenbaum, P., Paneth, N., Leviton, A., Goldstein, M., Bax Damiano, D., & Jacobsson, B. (2007). A report: The definition and classification of cerebral palsy April 2006. *Developmental Medicine & Child Neurology. Supplement*, 109, 8–14.
- Saldana, J. (2016a, July 28–29). *Coding and analyzing qualitative data* [Paper presentation]. 13th Annual Qualitative Research Summer Intensive, Chapel Hill, NC, United States.
- Saldana, J. (2016b). *The coding manual for qualitative researchers* (3rd ed.). SAGE.
- Sheridan, K. (2009). Osteoporosis in adults with cerebral palsy. *Developmental Medicine & Child Neurology*, 51(4), 38–51. <https://doi.org/10.1111/j.1469-8749.2009.03432.x>
- Simons, L., Lathlean, J., & Squire, C. (2008). Shifting the focus: Sequential methods of analysis with qualitative data. *Qualitative Health Research*, 18, 120–132. <https://doi.org/10.1177/1049732307310264>
- Stanley, M. (2015). Qualitative descriptive: A very good place to start. In S. Nayar & M. Stanley (Eds.), *Qualitative research methodologies for occupational science and occupational therapy* (pp. 21–36). Routledge.
- Strauss, D., Ojdana, K., Shavelle, R., & Rosenbloom, L. (2004). Decline in function and life expectancy of older persons with cerebral palsy. *NeuroRehabilitation*, 19, 69–78. <https://doi.org/10.3233/NRE-2004-19108>
- Strax, T. E., Luciano, L., Dunn, A. M., & Quevedo, J. P. (2010). Aging and developmental disability. *Physical Medicine and Rehabilitation Clinics of North America*, 21(2), 419–427. <https://doi.org/10.1016/j.pmr.2009.12.009>
- Thorpe, D. (2009). The role of fitness in health and disease: Status of adults with cerebral palsy. *Developmental Medicine & Child Neurology*, 51(4), 52–58. <https://doi.org/10.1111/j.1469-8749.2009.03433.x>
- van der Slot, W. M., Nieuwenhuijsen, C., van den Berg-Emons, R. J., Wensink-Boonstra, A. E., Stam, H. J., & Roebroek, M. E. (2010). Participation and health-related quality of life in adults with spastic bilateral cerebral palsy and the role of self-efficacy. *Journal of Rehabilitation Medicine*, 42(6), 528–535. <https://doi.org/10.2340/16501977-0555>
- van der Slot, W. M., Roebroek, M. E., Nieuwenhuijsen, C., Bergen, M. P., Stam, H. J., Burdorf, A., & van den Berg-Emons, R. J. (2013). Cardiovascular disease risk in adults with spastic bilateral cerebral palsy. *Journal of Rehabilitation Medicine*, 45, 866–872. <https://doi.org/10.2340/16501977-1185>
- World Health Organization. (2002). *Towards a common language for functioning, disability and health: ICF*. [www.who.int/classifications/icf/icfbeginnersguide.pdf?ua=1](http://www.who.int/classifications/icf/icfbeginnersguide.pdf?ua=1)

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