



“We do it all”: A qualitative exploration of the caregiver role for young adults with cerebral palsy

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ABSTRACT

Aim: To describe the complex roles of and crucial support provided by caregivers to young adults with cerebral palsy (CP) during the transition to adulthood.

Method: This was a qualitative study. We conducted 20 semi-structured interviews (13 caregiver; 7 patient/caregiver dyad) and analyzed data using a qualitative descriptive approach informed by phenomenological principles.

Results: We identified four major themes related to the roles that caregivers play during the transition to adulthood for young adults with CP: 1) caregivers as care coordinators; 2) navigating logistic and insurance barriers; 3) adjusting to adulthood and planning for an uncertain future; and 4) supporting maintenance of health, function, and quality of life. Overall, caregivers shared the many different ways that they act as advocates for young adults with CP. Many participants identified the extensive amount of time, energy, and financial resources required to appropriately provide care.

Conclusions: The transition to adulthood for young adults with CP is a challenging, uncertain, complex process for both adults with CP and their caregivers. Throughout this transition, caregivers also prioritize the happiness and quality of life of their adult children with CP. Our findings could be used by clinicians and researchers to develop and study patient- and family-centered transition processes for individuals with CP that attend to the struggles and priorities of youth with CP and caregivers alike.

1. Introduction

Cerebral palsy (CP) is a condition affecting the developing infant or fetal brain that impacts movement and posture, and can also impact other functional domains (e.g., communication, cognition, etc.). CP is the most common cause of physical disability and one of the most common causes of developmental disability in childhood.¹ Despite its onset in early childhood, individuals with CP are living longer, with the greatest improvement since the 1980s among those with severe CP.

Currently up to 90% of children with CP reach adulthood.^{2,3} The transition from childhood to adulthood can be made even more complex by the unique healthcare needs and risks of this population compared to individuals without CP. Compared to children with CP and adults without CP, adults with CP have a higher prevalence of cardiovascular, metabolic, respiratory, musculoskeletal, and psychological chronic conditions as well as multimorbidity and higher healthcare utilization and costs.^{4–10}

Supporters, parents, and/or guardians (hereon referred to as

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caregivers) of individuals with CP play a critical role in the coordination of this complex care, while also parenting (in such cases), providing day-to-day support, advocacy, insurance navigation, and management of supportive services.^{11,12} This is among many other competing responsibilities, sometimes to the detriment of their own health.^{11,13–15} Multiple prior studies have shown adverse physical health, mental health, and quality of life outcomes in caregivers of children with CP, particularly those requiring higher intensity of care.^{11,15–20} The role of the caregiver continues on through adulthood, in various forms, and caregivers often play a major role in guiding and supporting the transition to adulthood, including the healthcare transition.

This transition from pediatric to adult care can be particularly overwhelming for caregivers.^{21–24} It is often a chaotic, confusing, and frightening time, and poor transitions have been linked to worsening health, lower quality of life, inappropriate dependence on emergency services, and increased hospitalizations for patients.^{25–27} Family participation in the transition process has been associated with improved outcomes, yet despite the importance of a supportive transition, the burden of navigating the process is felt heavily by the caregiver.²¹ The objective of this study is to describe the complex roles of and crucial support provided by caregivers to young adults with CP during the transition into adulthood.

2. Material and methods

We conducted a qualitative study using semi-structured interviews of adults with CP and/or their caregivers. The Colorado Multiple Institutional Review Board deemed our study exempt.

2.1. Participants

Eligible participants were adults with CP aged 18 years or older and/or their caregivers who were English speaking, had not yet transitioned to adult rehabilitation care, and were seen in our institution's pediatric rehabilitation clinic at least once between July 2020 – June 2022. We used a maximum variation purposeful sampling approach^{28–30} for diversity of demographic background and level of function based on the Gross Motor Function Classification System (GMFCS) level.³¹ In maximum variation sampling, key variables are selected by the research team and then cases that vary from each other as much as possible are identified, allowing us to identify meaningful patterns from a diverse sample.³⁰

We screened the electronic health record (EHR) of eligible patients. Eligibility was further determined based on the above inclusion criteria. A member of the study team (CG) reached out to eligible participants. Although the legal decision-making status for a patient is not often clearly documented within the EHR, we contacted the designated legal decision maker or guardian when possible. If not clearly documented, we reached out to the primary contact listed in the EHR, which was either the patient, family member, or other caregiver/legal guardian. The primary contact was attempted by phone call and/or email up to three times. Both patient and caregiver(s) were invited to be interviewed unless significant cognitive, communication, and/or behavioral impairments precluded patient participation. This decision was made using a collaborative screening process created by the study team and conducted in partnership with the caregiver (Supplemental Content 1). In brief, when contacting a caregiver, we expressed our desire to interview adults with CP themselves as well. We cited significant cognitive, communication, and/or behavioral challenges as possible reasons for an adult with CP to not participate. If the caregiver felt the adult with CP could participate, we screened for elements of decisional capacity (understanding of research purpose and risks, voluntary nature of participation). For those cases in which the patient was able to participate, the decision to interview the patient and caregiver separately or in a dyadic interview was also made in conjunction with the participants.

2.2. Procedures

The study team developed the interview guide (Supplemental Content 2), based on the study objectives, prior research, input from our institution's Patient and Family Research Advisory Panel, and three pilot interviews (conducted by CG). Interviews took place from September 2022 – February 2023 over Zoom video conferencing or phone (depending on participant preference). All study team members who conducted interviews either had extensive qualitative research experience or participated in interview training (CG, CS, and JW). Any participants that had a direct clinical relationship with one of our study team's clinicians (CS, JW) were interviewed by our qualitative analyst (CG) instead. Verbal consent was obtained at the start of each interview, along with self-reported patient and caregiver demographic data that were entered into a secure REDCap electronic database hosted at the University of Colorado Anschutz.³² These data were all self-reported based on participant's identity and meant to inform our purposeful sampling strategy for diversity of background and level of function. Interviewers then guided a semi-structured conversation regarding the participant's priorities related to health and healthcare, experiences with pediatric rehabilitation care, changes in rehabilitation needs over time, and goals related to adult care. The same guide was used for individual and dyadic interviews. Interviews lasted 60–90 min. Interviews were audio-recorded with permission from participants and professionally transcribed (Landmark Associates; Phoenix, AZ). Transcripts were de-identified and entered into a qualitative software program for analysis (ATLAS.ti version 23; Berlin, Germany). Interviews were conducted until thematic saturation was reached based on team consensus that no new information was being received.³³

2.3. Data analysis

We used a qualitative descriptive approach informed by phenomenological principles to explore the lived experience and values of young adults with CP and their caregivers. A qualitative descriptive approach allowed us to explore, understand, and describe the perspectives of participants, and phenomenological principles allowed us to focus on the lived experiences of young adults with CP and their caregivers.^{34–37} The study team (CS, CG, JW) coded interview transcripts inductively, creating codes based on emergent data.³⁸ The team met regularly to reconcile and calibrate coded transcripts until a final codebook was developed.³⁹ The remaining transcripts were coded separately, with 20% double coded by two of the three coding team members (CS, CG, JW). Once coding was complete, we generated code reports (queries) that listed all associated quotations verbatim. Using traditional thematic analysis, we reviewed and summarized quotations within each report and identified salient themes.^{39,40}

3. Results

After contacting 105 eligible participants, we completed 20 interviews (13 caregiver interviews, 7 patient/caregiver dyadic interviews; 27 participants total). Based on our screening process described in Section 2.1, no adult with CP chose or was able to participate in an interview alone. Adults with CP who participated were between 18–40 years old, and the majority were male, White, and nonambulatory (GMFCS IV-V; Table 1). Most also lived with their primary caregiver at the time of their interview. Caregivers who participated were majority female and White (Table 2). All caregivers were parents, except for one who was a court-appointed legal guardian. Most caregivers had at least some college-level education and worked at least part time. We were able to include participants and caregivers who identified as Hispanic or Latinx, those who were bilingual, and those who lived in rural areas.

The goal of our study was to increase understanding regarding the experiences and values of young adults with CP and their caregivers

Table 1

Self-reported demographic data of adults with CP. Presented as n (%) unless otherwise stated.

	Adults with CP
Age: mean (SD)	24 years 4 months (6 years 4 months)
Gender	
Male	12 (60%)
Female	8 (40%)
Race and Ethnicity	
White	19 (95%)
>1 race	1 (5%)
Hispanic or Latinx	4 (20%)
Not Hispanic or Latinx	16 (80%)
Functional mobility*	
GMFCS I-III	5 (25%)
GMFCS IV-V	14 (70%)
Unknown	1 (5%)
Rural zip code**	2 (10%)
Bilingual participants	1 (5%)
Primary insurance	
Medicaid	9 (45%)
Medicare	2 (10%)
Tricare	1 (5%)
Private	8 (40%)
Secondary insurance	
Medicaid	8 (40%)
Medicare	1 (5%)
None	11 (55%)
Highest education level	
Less than high school degree	1 (5%)
High school degree (GED or equivalent)	17 (85%)
Some college	2 (10%)
Employment	
Unable to work due to disability	12 (60%)
Unemployed	6 (30%)
Employed, part time	2 (10%)
Living with primary caregiver	18 (90%)

*GMFCS categories combined into ambulatory (I-III) and nonambulatory (IV-V) given small cell counts in certain categories in order to preserve anonymity *

**Based on zip code per Federal Office of Rural Health Policy Data Files⁴⁹ CP – cerebral palsy SD – standard deviation GMFCS – Gross Motor Function Classification System GED – General Educational Development Test

about pediatric rehabilitation-related care and perceived barriers and potential facilitators to healthcare transition. To this end, we identified major themes related to the value and security of long-term relationships identified by adults with CP and caregivers alike; difficulty navigating the complexities of transition for both adults with CP and caregivers; and differences in the pediatric vs. adult models of care and providers complicating the transition for adults with CP and caregivers (publication forthcoming). However, related to the many roles that caregivers play during the transition to adulthood for young adults with CP, we also identified four themes fully explored here: 1) caregivers as care coordinators; 2) navigating logistic and insurance barriers; 3) adjusting to adulthood and planning for an uncertain future; and 4) supporting maintenance of health, function, and quality of life.

Overall, caregivers shared the many different ways that they act as advocates for young adults with CP. Many participants identified the extensive amount of time, energy, and financial resources required to appropriately provide care. A mother shared that managing her daughter’s many providers and medical needs was like “managing a small business” (Participant 2). From coordinating care to providing day-to-day physical support, a handful of parents shared the feeling that they were “everything” to their adult child with CP.

“We do have medical power of attorney. We are his legal guardians. We did that when he turned 18. He can’t consent to a lot of the medical procedures and surgeries. We are his—we do all that for him. In fact, we do everything for him, physically. We’re his financial advisors. We do it all.” (Participant 8, mother of a young man with CP in his early 20s).

Table 2

Self-reported demographic data of caregivers. One participant was not a caregiver and instead a court-appointed legal guardian; their demographic data are excluded. Presented as n (%).

	Caregivers
Gender	
Male	2 (10%)
Female	17 (85%)
Race and Ethnicity	
White	19 (95%)
>1 race	1 (5%)
Hispanic or Latinx	3 (15%)
Not Hispanic or Latinx	16 (80%)
Rural zip code*	2 (10%)
Bilingual participants	3 (15%)
Highest education level	
High school degree (GED or equivalent)	2 (10%)
Some college	5 (25%)
Associate’s degree	3 (15%)
Bachelor’s degree	4 (20%)
Master’s degree	4 (20%)
Doctoral degree	1 (5%)
Employment	
Employed, full time	14 (70%)
Employed, part time	3 (15%)
Homemaker	1 (5%)
Retired	1 (5%)
Annual household income	
\$20,000-\$34,999	2 (10%)
\$35,000-\$49,999	0 (0%)
\$50,000-\$74,999	2 (10%)
\$75,000-\$99,999	3 (15%)
>\$100,000	12 (60%)
Additional children [^]	
Yes, <18 years old	4 (20%)
Yes, >18 years old	13 (65%)
No	4 (20%)
Who does caregiver provide daily care to? [^]	
Patient	15 (75%)
Spouse/partner	3 (15%)
Other children <18 years old	4 (20%)
Other children >18 years old	2 (10%)
Grandchild(ren)	1 (5%)
No one	1 (5%)
Who does caregiver live with? [^]	
Spouse/partner	15 (75%)
Children >18 years old	17 (85%)
Children <18 years old	4 (20%)
Paid in-home caregiver/aid	1 (5%)
Other family members	1 (5%)

*Based on zip code per Federal Office of Rural Health Policy Data Files⁴⁹

[^]Participants could select multiple choices GED – General Educational Development Test

Many participants detailed their experiences assuming the role of researcher, advocate, and navigator in order to figure out what works best for their adult child. Caregivers spoke to the amount of effort and advocacy required to find the right provider, the best fitting day program, the right equipment or procedures, the most appropriate plan for future care, etc. (Table 3).

3.1. Theme 1: “That management aspect is a full-time job” (Participant 2) - caregivers as care coordinators

Caregivers often provided advanced levels of care coordination for their adult children with CP. Many participants recalled the significant effort required in forming their or their child’s pediatric healthcare team. This includes the amount of time and energy it can take to find good providers, particularly if the caregiver is lacking resources or works outside the home. Once a care team is established, it can still require a great degree of effort to effectively coordinate care amongst different providers and specialties. Many participants recalled times where they had to communicate information and recommendations

Table 3
Identified themes with exemplar quotes.

Representative quotes
<p>Theme 1: Caregivers as care coordinators</p> <p>"I am the only care provider that we have, so navigating transporting our typical son to and from school and his activities, assisting <Patient Name>'s sister with her transportation needs, and then making sure that <Patient Name> gets to his stuff, some days I only have an hour where I'm not driving." (Participant 1, mother of a young man with CP in his early 20s)</p>
<p>Theme 2: Navigating logistic and insurance barriers</p> <p>"...it was frustrating when he turned 18. It seemed like they didn't want to treat him in a sense. I'm like nothing has changed. He still has CP. He's still a blind man, and he's having more problems, or he's getting stiff on this side from doing different activities. From high school to adulthood, things have changed. It just seems like the insurance, more so, didn't want to—I don't know, they needed more reasoning to get it approved." (Participant 6, mother of a young man with CP in his early 20s, during a dyadic interview)</p> <p>"I think sometimes I get a little intimidated because now that <Patient Name> is involved in the adult services, and he's on the DD waiver, any time we have to make any med changes, it's such a huge amount of paperwork that I feel sometimes that that's part of the problem is that I don't want to schedule those appointments. If I forget a form, then we have to follow-up, and we can't get the meds until this and this happens. I think sometimes that can be some of the issues I have with making those med changes...If <Patient Name> is on any medication that's considered a mood-stabilizer medicine, then we have to go through the human rights committee, and it's just so much stuff where I almost kind of feel, at times, that if you're not rocking the boat, it's a little bit easier" (Participant 1, mother of a young man with CP in his early 20s)</p>
<p>Theme 3: Adjusting to adulthood and planning for an uncertain future</p> <p>"Then when I'm too old to do it, I don't even know who to hire. No one in Medicaid has been—Medicaid is the way into a lot of things, right? Even if I can private pay for something, my access is through Medicaid, right? I don't know how privately, and I don't know how through Medicaid to get someone to be me. Who manages all this? I have asked so many different ways, so many different people, and no one has answered. They're like, 'Oh, wherever she's living.' I'm like, this is not doing the laundry. This is a fulltime job, the management part. No one has told me who does this. All of a sudden, who—I don't know if anyone will do it." (Participant 2, mother of a young woman with CP in her late teens)</p> <p>"I'm his legal guardian. If Medicaid calls and they have to just talk to him, I need to be able to talk...As far as finances, he's got the Medicaid, and he gets Social Security. I oversee; I'm the main one. That's a huge fear for me, if something happens to me. It's just like I'm the manager; I'm the financial. It takes a lot more money than what you get from Medicaid for me to keep this house going and whatnot. I'm the one who, when he has COVID, nobody comes around, and I'm with him for 14 days in a row. I do all the lifting when I'm 64 years old. Luckily, I work out, and I'm strong, all those kind of concerns. I've got awesome care providers, but you get into these emergencies. I've gotten to the point, traveling with him, that I always take somebody, 'cause I'm just afraid, "Oh my God, if something should happen to me. Here's this non-verbal person on an airplane, just stuck." Anyway, I'm thinking about those things." (Participant 10, mother of a young man with CP in his mid-30s)</p>
<p>Theme 4: Supporting maintenance of health, function, and quality of life</p> <p>"He's [the patient] not gonna walk again. His speech will—as—his speech isn't gonna increase or—well, it did decrease, but it's not gonna get better, so no, there's—he's an adult. All those other things, we went through already. Right now, all we wanna do is maintain his physical being, so whatever it takes to do that. We're not concerned about going to the next level of education or anything like that," (Participant 8, mother of a young man with CP in his early 20s)</p> <p>"...Maintaining his health and growth. His body's potential, I guess I mean to say. Trying to really pay attention that we don't miss things as time goes on, as far as if his body starts changing. I guess it is a little different as an adult. Growing up we were just always working on growth and stuff like that, but now he's kind of plateaued in that area and we just wanna maintain the best health we can for him and that's in posture and in his body health and mental health, happiness, social health. Just we strive very hard to give <Patient Name> as typical of an experience as we're able while accommodating all of his needs" (Participant 18, mother of a young man with CP in his late 20s, during a dyadic interview)</p>

between providers of different specialties due to fragmented care. Participants shared examples such as coordinating differing interventions so that they didn't conflict and arranging necessary blood draws during an unrelated procedure to avoid repeated trips to the clinic or hospital. Predominantly, however, participants discussed the need to be an advocate for their adult child or client, particularly when needed care is not being provided. Caregivers described situations such as needing to be a "squeaky wheel" and call an orthotics department multiple times to receive their orthoses (Participant 2) and needing to explain to

unfamiliar providers when something is wrong with their child, sometimes going to many different doctors to seek help. One participant described her experience with care coordination.

"...Look, I'm an old parent. I've been doing this for a very long time. It took me a long, long time, and a lot of pain and a lot of discipline, the discipline. Well, we're gonna draw blood this week. Well, we just drew blood last week. Well, we're gonna draw blood again over here because this isn't the same blood I use for this. These are the kinds of things that the adult world 'cause [pediatric healthcare system] does it better than—but there's still things in [pediatric healthcare system] where I ran into that same thing. It would be like this doc didn't talk to that doc. The fact is when you have a multi-disciplined patient, it would be so wonderful and helpful to that patient and to the family if these kinds of things might be able to be acknowledged and handled." (Participant 14, mother of a young woman with CP in her early 30s).

Caregivers highly valued providers that can see the "big picture" and communicate directly and effectively with other care team members. Another caregiver described the value she places in collaborative processes at her adult child's pediatric hospital:

"Yeah, their teamwork. They share their ideas with us while we're there. Even after we leave, they said, "Oh, hey, this is what we were thinking after you guys left...How do you feel?" You can sense connectedness, the teamwork. Really good communication with these doctors." (Participant 6, mother of a young man with CP in his early 20s, during a dyadic interview).

This pediatric "dream team" (Participant 2) can also be a barrier to transitioning to adult healthcare, as many participants had concerns about recreating this team in the adult setting. Specific concerns included lack of identified adult providers to care for patients with childhood-onset medical complexity or disability, logistical difficulties related to wait lists and insurance barriers, and the overall amount of time necessary to make this transition on top of all other responsibilities. This was especially true when participants felt that they had to find adult providers on their own, without the support or guidance of their pediatric care team. One caregiver described her experience with the amount of effort and work that it has taken to find new, adult providers for her son:

"Our concern is what happens when he finally leaves [the pediatric healthcare system]? We don't know where to go from there right now. It's difficult to find these facilities on your own. <Name> will send you all kinds of lists of different facilities and stuff, but you have to do all the paperwork. You have to do all the footwork, and that's another problem is if you have the time, that's great, but we were both working adults until I retired. I don't know about other families. I'm sure there might be a full-time caregiver, but in this economy, you need two incomes. It's just sometimes it can be exhausting and overbearing and everything else." (Participant 8, mother of a young man with CP in his early 20s).

For many participants, this transition period is a vulnerable time for gaps in care. When these gaps occur, caregivers may be compelled to make medical decisions beyond their comfort level or scope. One parent shared her experience being unable to find an adult specialty provider and experiencing a gap in care for her adult child, making her feel as though she was taking on the role of a medical care provider without the essential expertise:

"The pain clinic, actually, did when [my child] turned [late teens], kicked us out of the program...They're like, "So sorry. This is the end. This is the last time you get to see us." I was like, "Oh, darn. Where do we go?" They said, "Well, there's a great pain team at <Hospital>." I was like, "Oh, great. It's just across the street. I'll call and make an appointment." They had a two-year wait list to see consumers with Medicaid...It was a huge

barrier and something that was really a big deal. A lot of the providers here in <City>, being just family medicine, didn't feel comfortable at all with the level of medications that [my child] was on...I got into some situations where I was making decisions that I didn't feel like I had the knowledge to make. That was really kind of the first time, and I was like, this is some chemistry that I have no education in. We're just giving [my child] stuff, and this doesn't feel good. That was a big thing for us" (Participant 12, mother of a young man with CP in his mid-30s).

Other participants also recalled concerning gaps in care during this transition period. During an exacerbation of one of her daughter's co-occurring medical conditions, one participant went from doctor to doctor while each of them told her that the problem was outside their area of expertise. She ultimately escalated her concerns to hospital leadership, which resulted in them being able to establish appropriate care. Another parent shared an anecdote about receiving verbal permission to schedule her adult child with a pediatric provider, but then encountering barriers when trying to make this appointment. She recalled having to make numerous phone calls to make this appointment, and described how each phone call takes away from being able to care for her son.

"...when I tried to get an appointment with Dr. <Name>...The barrier at the scheduling office was difficult 'cause she's like, "Oh, no, he's 19. He can't have an appointment here," or whatever he was at the time. I was like, "But Dr. <Name> said we could." She's like, "No, you can't," and that was the end of the conversation. I actually called <Name>, who called Dr. <Name>, who told the scheduler, "No, you need to make this appointment." That goes from one phone call for me to, like, five phone calls for me, which as you can tell, I manage my level of effort that I have to put into something and how many phone calls I have to be on...Well, the problem is that [my child] takes 24-hour care, so each phone call, if it takes me 15 min, might lag back whether or not he's getting changed on time or taken care of in a timely manner. It's an issue, and I have to schedule his care around what anybody else might be a 15-minute phone call" (Participant 12, mother of a young man with CP in his mid-30s).

3.2. Theme 2: "So many hoops" (Participant 1) - navigating logistical and insurance barriers

The process of coordinating, scheduling, and managing the logistics of care needs can be a full-time job for caregivers of young adults with CP, in addition to the daily level of physical care required. One parent shared that there are 15 people in her daughter's life providing some sort of weekly service. At least once per week, someone cancels, requiring additional time, communication, and coordination to rearrange the schedule and accommodate. Similarly, another parent shared navigating appointments for not just her son, an adult with CP, but her two other children. Additional logistical challenges identified by participants included managing medications and getting refills, the time/distance required to travel to appointments or accessing transportation itself, and appointment and procedure scheduling. Many of these logistical barriers in turn created additional work on the part of the caregiver.

Two caregivers shared how they avoid certain medications or procedures due to the constant level of effort required. One parent shared that the amount of paperwork required whenever her adult child has a new medication motivates her to avoid such changes and prevent "rocking the boat." Another parent broke down the steps required to schedule a seemingly simple procedure.

"We did Botox injections and phenol injections for years, years and years...They were successful, but it was always—so the struggle that I had with the injections is there's always this window where everything's great, and if you could plan your whole life in that three-month window when everything's great, that would be fantastic...There's so much scheduling

life around the event of getting the injections... There's this staggering thing that just became too much for me to manage or I stopped wanting to, I suppose." (Participant 12, mother of a young man with CP in his mid-30s).

One of the most pervasive themes, regarding logistical challenges, cited by caregivers was the navigation of insurance coverage, and the frequency and intensity with which caregivers need to advocate or "fight" to seek payment for a necessary service. Parents and caregivers reported the challenges with getting insurance to pay for therapies and equipment. One parent described "pleading and crying" with the insurance company to pay for a new wheelchair that her child desperately needed, but not being able to get one covered for two years. One caregiver shared her experience with "fighting" insurance companies.

"Oh, my gosh. He's in an Aspen seat. Years ago, during the last recession, we had—he'd already had one or two Aspen seats, and we were going for the next one. They were saying, "Nope, you can't have it. Can't have it." Kept denying it. I was calling and calling. Finally, I had to get an advocate 'cause I had called Medicaid, and the lady is like, "Ma'am, it's like you need a Volkswagen, and you're asking for a Cadillac." That has still stuck with me to this day. It's just those things where people are sitting and making decisions for you that don't know the day-to-day, like, "Why would you need an Aspen seat? Why would you need a certain Hoyer lift? Or why would you need a—this piece?" In his wheelchairs, he has it where it raises up and down, and trying to justify—so it's just always constantly having to justify, "Why do you need this?" (Participant 13, mother of a young man with CP in his early 20s, during a dyadic interview).

While many described having to advocate with insurance companies, several participants felt that this issue was exacerbated as the individual with CP was entering adulthood, which often resulted in changes in insurance coverage:

"Trying to fight for one little thing is just so tiring for people who have been doing this their whole lives. If it was the same as it was when he was younger, you can handle that, but it's virtually impossible. They just will give nobody therapy unless you have a surgery or you go in with some major [problem]." (Participant 10, mother of a young man with CP in his mid-30s).

If insurance does cover a service, participants reported long wait times or prolonged back and forth paperwork with appeals. This is particularly an issue for equipment repairs, as families can be left without critical equipment for weeks or even months. If insurance will not cover the request, participants are left without services, or with broken or ill-fitting equipment. At times, they find themselves paying out of pocket, or circumventing insurance companies altogether and going straight to the source:

"...Medicaid is super slow to approve any repairs. Unless we can anticipate something breaking ahead of time and be on top of it, if something breaks, we're pretty much duct taping things together to make it work... For example, last week, <Name> broke the buckle on his <Business> shower chair, and I knew that if I went through our equipment provider that it would be over a month before we would get a replacement part. I called <Business> directly and asked them if we could just purchase a replacement belt on our own, which is \$100. They said because it broke, they were going to just send us one for free. We should be getting that any time in the next day." (Participant 1, mother of a young man with CP in his early 20s).

A court-appointed guardian to an adult with CP shared her difficulties getting her on an appropriate waiver through Medicaid in order to get coverage for a private-duty nurse as a respite to the single parent providing high-level 24/7 care. Several participants noted the catch-22

of needing two incomes to support all of the expenses not covered by insurance, but also needing a caregiver to take on the full-time job of coordinating and managing care. Relatedly, participants felt that insurance companies do not recognize or place value on the sheer amount of care management and coordination that goes into providing care to their children.

“Medicaid won’t acknowledge that... I get up crazy early, and this is what I do all day except my little parttime job that I squeeze in ‘cause I need the money. It’s crazy, but no one—I’m not looking for empathy. I’m looking for the system to acknowledge that that case management, that management aspect is a fulltime job when you have someone who’s this complicated and complex.” (Participant 2, mother of a young woman with CP in her late teens).

3.3. Theme 3: “Crystal ball is not great” (Participant 2) - adjusting to adulthood and planning for an uncertain future.

Participants commonly brought up the new roles, challenges, and decisions they faced when they or their child with CP entered adulthood. For caregivers, supporting their adult children in these new roles brought its own joys and struggles. One major change reported by many was graduation from high school and/or a school-based transition program. Many participants discussed the possibility or plan of their young adult with CP transitioning into an adult day program, with the goal of increasing independence with life and social skills. Several participants with CP were working, applying for jobs, or pursuing vocational training. For others, vocational training and/or life skills training remained an unmet need. One participant had difficulty finding an appropriate program for their adult child, one which offered the amount of care he required for his significant physical disability, but still provided intellectual stimulation to meet his cognitive needs:

“His time’s too valuable. His interests are bigger than that.” (Participant 18, mother of a young man with CP in his late 20s, during a dyadic interview).

Another important decision many participants faced upon entering adulthood was the question of who would support their or their adult child’s decision making. Many participants had a formal arrangement in place, either through formal guardianship or a power of attorney, while others supported their adult child’s independent decision making. One participant that did pursue guardianship for her child acknowledged the gravity of such a decision and the importance to pursue it thoughtfully:

When we went through the guardianship, we had a fantastic judge that basically lined it out. Even after I’d done everything, he said, “You realize you’re taking somebody’s rights away,” which I thought was really great, and I appreciated that he said it to me. I feel like it’s something that should be said more in the process earlier. It’s not just your child for the rest of your life. This is a person, and you’re taking their rights away from them.” (Participant 12, mother of a young man with CP in his mid-30s).

Establishing a plan for care beyond guardianship also worried caregiver participants. Many expressed concern and uncertainty regarding who would provide, coordinate, and manage the care of their adult child with CP once their current caregiver was unable to do so. They worried that their child’s function and health would worsen without their level of commitment, and some reported planning ahead for that now, by trying to accumulate resources.

“I anticipate it will—that her needs will increase over time. Her physical strength, despite all the exercise and all the PT, I don’t see it improving. I see it holding stable with monumental Herculean effort. She’s 19. I’m 51. I can’t do that forever. Crystal ball is not great. I think once it’s not me—she’ll get less. Then I think her aches and pains and her ability to

stand up and all that will get worse and worse.” (Participant 2, mother of a young woman with CP in her late teens).

Social and emotional challenges can also make the transition to adulthood difficult for young adults with CP. Several participants described the increased expectations that accompany increased independence, relational struggles, and social isolation. For one participant, this was exacerbated for her adult child with CP seeing his younger two siblings graduate high school, go off to college, and live independently. Another participant thought that a social or support group may help with some of these struggles in the transition to adulthood.

“I think, honestly, the onus is much more on her now. She’s gotta own this. I think that’s a struggle. I’ll tell you what else is a struggle right now, is the emotional piece, the psychological piece, of identifying yourself as a person with CP...She may speak about it, but I think that’s very different than accepting that within yourself. She is a beautiful young woman. A lot of young women her age, they have boyfriends. I don’t even think she sees herself as desirable in that way, because I think she sees herself as a person with a disability. That’s very sad to me.” (Participant 4, mother of a young woman with CP in her early 20s).

Conversely, many participants also described exciting opportunities during the transition to adulthood. A couple of participants reported that their adult child had taken on an advocacy role, sharing information with their community “to teach them about how he’s a real human being that has an incredible life that is worth living” or influencing legislative policy related to individuals with disabilities. One was also in college and conducting disability-related public health research. Others were participating in skiing, paddle boarding, archery, theater, volunteerism, and brewery tours with their family in an adapted bicycle.

3.4. Theme 4: “An incredible life that is worth living” (Participant 10) - supporting maintenance of health, function, and quality of life

In addition to all of the roles and responsibilities that caregivers endorsed, they also shared highly valued aspects pertaining to the care and health of their children with CP. Comfort and stability were frequently noted as the most important aspects. Caregivers spoke about an evolution of their values over time. When their children were young, families focused on improvement and functional gains. Now that their children are adults, the focus had shifted to maintenance and quality of life. Caregivers shared their tendency to avoid interventions that cause discomfort, such as surgeries or invasive procedures, or that take away from their child and family’s enjoyment of life. They discussed the overwhelming number of appointments that patients had as youth, when they were trying to “improve.” As one caregiver explained:

“...As he’s [my child] entered adulthood—when he graduated high school, he was so stressed out with schedule and his life being about kind of meeting everybody’s demands of him that we really backed off on—and his needs were just maintaining, so from what we’ve known and learned throughout his life we still apply and when his needs change, we call in specialists then kind of thing. We’ve gained so much knowledge through his years from all the specialists that it seemed to serve the quality of his life much better to just be able to let him live his life instead of go to appointments his whole life” (Participant 18, mother of a young man with CP in his late 20s, during a dyadic interview).

Some caregivers shared that their loved one had “plateaued” and that the focus is on day-to-day maintenance and stability of their baseline. Along these lines, some participants also noted the importance of catching new issues that arise in adulthood so that they do not cause pain or a loss of function.

“I would say definitely trying to keep [my child] at his baseline and avoid him dipping below that baseline. That’s been really important for us

because we do, do a lot of this and trying to stay at baseline. I don't think we're ever gonna get better than baseline, but it's important that we don't drop below baseline. For example, he has an ileostomy now, and we've had to have a couple revisions. We're very hesitant to do more surgeries on <Name> unless it's absolutely necessary, but in order to stay at that baseline, we've had to do a couple revisions" (Participant 7, mother of a young man with CP in his mid-20s).

A handful of caregivers shared the value they placed on enjoyment for their adult children – focusing on quality of life and experiences, as opposed to medical interventions to improve range of motion, musculoskeletal alignment, etc. One caregiver clearly articulated this perspective:

"Well, at this point, and those goals, for us, have evolved over the years, to be certain, but at this point, it's largely just keeping him comfortable... Things that we would've pursued in the past, like braces and all of that stuff to try to correct things, we don't do any of that anymore because comfort, no matter how contorted limbs get, comfort comes first... Just from an orthopedic standpoint, we put all of the effort into trying to keep all of the body parts as moving, and we did all the therapy and all of that all the time. We worked super hard at everything for the beginning half of his life. Then we started to look at—my Facebook feed would run through, and it was only hospitalizations and then discharges, hospitalizations and discharges. We decided as a family that we'd rather have memories in photo books... That was our choice at that point. We actually drafted a DNR at that point... and then immediately we went to Mexico and hung out on a beach. We still did surgeries after that, but it was only—at that point, it was only in an effort to make him comfortable, not to continue having range of motion or anything of that nature." (Participant 12, mother of a young man with CP in his mid-30s).

Another caregiver described the many social and recreational activities that brought joy and fulfillment to her son's, a young man with GMFCS level V CP, and their family's lives:

Yeah, he has an incredible life. He skis. They call him "Big Air [Name]," and we actually have a movie of him, if anybody ever wanted to see about him out skiing and just the life that he lives. He showed it yesterday at the [Hospital] just to teach them about how he's a real human being that has an incredible life that is worth living. He works with a program [...] He goes paddleboarding with them. He's done archery with them. They do a play in the summer. He skis once a week with an adaptive assistant. He's in the community, goes to church here." (Participant 10, mother of a young man with CP in his mid-30s).

Some caregivers did, however, speak to specific medical priorities for the patient – such as flexibility and muscle tone, stamina, contracture prevention and correct positioning, vision care, the search for appropriate specialists, and future healthcare planning, access to therapies, cleanliness and prevention of pressure injuries or acute illness, mental health, and respite care.

4. Discussion

While the original goal of our study was to increase understanding of the values of young adults with CP and their caregivers regarding pediatric rehabilitation-related care and goals related to adult rehabilitation care (publication forthcoming), we found prominent themes regarding the crucial support provided by caregivers to young adults with CP during the transition to adulthood. Through semi-structured interviews and a descriptive approach to thematic analysis, we found that caregivers of young adults with CP transitioning to adulthood often function as care coordinators, navigate numerous logistic and insurance barriers during the transition process, face challenges in adjusting to adulthood and planning for an uncertain future, and strive to optimize the health, function, and quality of life of their adult children.

Caregivers of individuals with CP who are transitioning from pediatric to adult care carry a significant burden of care coordination and planning, and that load continues well into their children's adulthood. Prior studies have shown higher levels of caregiver burden, emotional stress, depression, anxiety, and pain; worse sleep quality; and lower quality of life in caregivers of children with CP, compared to caregivers of children without CP. This is exaggerated in those with higher levels of medical complexity, physical disability, or behavioral problems.^{11,15-20} One study found that female caregivers of children with CP had poorer physical and mental health than their male counterparts.¹³ Families of individuals with CP have also been shown to have higher levels of financial challenges, which may further exacerbate many of these issues. Moreover, those with higher time pressure (i.e., the amount of time required to accomplish a task is greater than the amount of time available) may also more frequently experience depression.⁴¹ Conversely, collaborative caregiving, functional family dynamics, and better financial status may improve some of these caregiver outcomes.^{11,42} While our study did not explore these specific outcomes among caregivers, we similarly found caregivers performing high levels of advocacy and care coordination for their adult children and navigating countless logistical, financial, and insurance barriers. In many healthcare systems, care coordinators help support patients with disabilities and complex needs and their families in accessing and coordinating intensive use of health-related services.^{43,44} A dedicated transition service coordinator could support the transition to adulthood for youth with CP and other disabilities, thereby easing the burden of care and coordination for families.⁴⁵

The transition to adulthood is an especially vulnerable time for youth with disabilities and their caregivers. This healthcare transition is often accompanied by changes in insurance coverage, decreases in access and adherence to appropriate treatments and services, worse health outcomes, and inappropriate reliance on emergency services.⁴⁶ Adolescents and young adults with disabilities require more guidance and support with care coordination during the transition period, as do their caregivers by extension.^{26,47} This again highlights the opportunity for a transition service coordinator to support this process, as described above. A recent systematic review found that individuals with CP during and post-transition had higher levels of housing instability and unemployment, difficulty forming relationships, and increased hospital utilization but decreased use of rehabilitation services.²¹ Family participation was one factor associated with improvement in these outcomes, and therefore supporting the caregiver(s) during the transition to adulthood is an integral part of the overall transition process.²¹ Despite the importance of family involvement, our study participants found navigating the landscape of adult care to be daunting and overwhelmingly complex.

Beyond connecting with the right care team members in adulthood, caregivers expressed the goal to go beyond life sustaining healthcare, and work on meaningful engagement in activities that will enhance the quality of life for their loved ones as they age into adulthood. Caregivers in our study emphasized the importance of their adult children's *quality* and *enjoyment* of life, often through social and recreational opportunities. Other studies described quality of life in children and adolescents with CP,⁴⁸ but this study adds to this evidence base by exploring how caregivers of adults with CP prioritize quality of life during the important transition to adulthood. This can be challenging when facing an uncertain future, with changing roles for both the young adult with CP and family members. Caregivers in our study spoke to this difficulty, which has been supported by other qualitative studies of caregivers of adolescents and young adults with severe CP.^{23,24} Similarly, the well-being of the parent is often intimately tied to that of their child.²⁴ As such, supporting caregivers and families during the transition process is likely to also benefit the young adult with CP by minimizing caregiver burden and optimizing quality of life for the entire family. Healthcare transition processes and programs must attend to the critical role of the caregiver and provide adequate supports and resources to ensure a

successful transition.

Our study has several important limitations. This work was conducted at a single academic pediatric health system in the United States, specifically in the pediatric rehabilitation clinic. As such, the transferability may be limited to similar contexts. Caregivers that participated in interviews were majority female, White, educated, and employed, and most adults with CP who participated or were represented had more severe physical disability (GMFCS IV-V). Most adults with CP in our study also lived with their primary caregiver(s) and were unemployed or unable to work. These factors may also limit transferability to individuals of different backgrounds. However, we were able to interview a diverse set of participants from a variety of education levels as well as participants living in rural settings and bilingual participants. Additionally, while dyadic interviews allowed us to include adults with CP with cognitive and communication difficulties, including those using augmentative and alternative communication devices, it was difficult to capture extensive discussions of patient experience and thus direct quotations presented here are from caregivers only. Additionally, no adult with CP chose to interview by themselves, which may have affected our findings.

5. Conclusions

The transition to adulthood for individuals with CP is a challenging, complex process for both adults with CP and their caregivers. Caregivers face many logistical barriers in the face of adult children's evolving needs which often require high levels of care coordination and advocacy. This period of transition is often accompanied by uncertainty and associated anxiety. Throughout this transition, we found that caregivers also prioritized their adult children's happiness and quality of life. To be consistent with the values of adults with CP and their caregivers, successful healthcare transition processes should incorporate quality of life as a highly important metric. Our findings could be used by clinicians and researchers to develop patient- and family-centered transition processes for individuals with CP that attend to the struggles and priorities of youth with CP and caregivers alike.

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Ethical Statement

The Colorado Multiple Institutional Review Board deemed our study exempt.

Verbal consent was obtained at the start of each interview, along with patient and caregiver demographic data that were entered into a secure REDCap electronic database hosted at the University of Colorado Anschutz.

CRedit authorship contribution statement

Sarmiento Cristina A.: Conceptualization, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Visualization, Writing – original draft, Writing – review & editing. **Glaros Chloe:** Formal analysis, Investigation, Methodology, Project administration, Software, Validation, Writing – original draft, Writing – review & editing. **Solomon Sanders Jessica:** Conceptualization, Writing – original draft, Writing – review & editing. **Wyrwa Jordan M.:** Conceptualization, Formal analysis, Investigation, Writing – review & editing. **Dorsey Holliman Brooke:** Conceptualization, Methodology, Resources, Supervision, Writing – review & editing. **Brenner Lisa A.:** Conceptualization, Methodology, Resources, Supervision, Writing –

review & editing.

Declaration of Competing Interest

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Data availability

Data will be made available on request.

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Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.hctj.2023.100039](https://doi.org/10.1016/j.hctj.2023.100039).

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