Attendant Care for College Students with Physical Disabilities Using Wheelchairs: Transition Issues and Experiences

Nequel R. Burwell
University of Tennessee

Roger D. Wessel
Thalia Mulvihill
Ball State University

Abstract

From preschool through high school, accommodation and success, rather than self-advocacy and student development, are the predominant frameworks for students with physical disabilities. Many students with physical disabilities who use wheelchairs are assisted by their family members with daily life activities such as getting out of bed, showering, eating, dressing, and toileting. Once in college, many of the students are responsible for finding their own personal care, thus it may be the first time they will have to self-advocate. Multiple factors affect the transition and experiences from high school to college and for students with physical disabilities, that transition may involve attendant care. This study explored the transitional attendant care issues and experiences of college students with physical disabilities who use wheelchairs. During a phenomenological study of 12 undergraduates, seven themes emerged regarding transitional issues for students with attendant care: time management, preparing for attendant care, training attendants, first feelings, accepting responsibility, parental involvement, and financial considerations. Four themes emerged regarding their collegiate experiences with attendant care: preferences, relationships with attendants, supportive friends, and characteristics of attendants. Recommendations for future studies, future researchers, academic and student affairs educators, and future college students are provided.

Keywords: Students with disabilities, physical disabilities, attendant care, self-advocacy

Imagine, as a college student, waking up at 7:30 am with someone you barely know standing in your room. This person informs you that they are here to help you prepare for your day, by helping you shower, get dressed, and attending to any other personal hygiene or health-related issues before departing to class. This brief imagery gives insight into the everyday routine of many college students with physical disabilities (SWPD) who use wheelchairs and have attendant care. As these students begin college, they are engaged with many of the typical first-year college student challenges, such as taking steps to becoming independent, becoming socialized into a new environment, and learning to live with new and different people. However they are also faced with some more unique challenges, such as becoming responsible for the process of hiring an attendant for themselves.

During elementary and secondary education, accommodation and success, rather than self-advocacy and student development, tend to be the central underpinnings for understanding how educational institutions construct learning outcomes for SWPD (McCarthy, 2007). Often pre-college students with disabilities who use wheelchairs are not expected to focus on self-advocacy skills as few have personal care responsibilities at that age because a parent or guardian handles all school-related issues and most of the personal care needs.

> When most of these students arrive at college it is the first time they have had to find—and use—his or her own voice. . . . almost overnight, students move from a system in which someone else such as a parent or teacher managed the "disability thing" to a completely self-directed system. (pp. 11-12)

Students have to assume personal responsibility when they come to college. "Colleges are not required to provide personal care assistance, and their responses will run the gamut from being completely hands-off the process, to providing assistants, to providing help in hiring an attendant" (Tiedemann, 2012, p. 69). This experience can be unsettling, from one day being a person with a physical disability whose personal care needs are met by family members, to being a first-year college student with the responsibility for personal care needs through the process of hiring an attendant (someone they do not know) to assist them. Studying the transitional issues and experiences of college SWPD who have attendant care and use wheelchairs helps others to better understand how these experiences affect these college students as individuals and shape their development.

Literature Review

In the absence of a set of student development theories focusing exclusively on SWPD, the authors selected a broad-based, often cited, theoretical framework for this study, namely Chickering and Reisser's developmental vectors for college students. Chickering and Reisser (1993) identified multiple vectors as a conceptual map to help determine identity-related issues during the collegiate experience. These vectors, or major developmental stages, build upon each other and provide a comprehensive overview of psychosocial development during the undergraduate years. Several of the vectors may be experienced differently by SWPD than by other sub-populations of college students (i.e., developing competence, moving through autonomy toward interdependence, developing mature interpersonal relationships, establishing identity). Physical and interpersonal competence may differ for SWPD. For a SWPD using a wheelchair, achieving higher levels of autonomy may look different than for students without physical disabilities.

The challenges of autonomy arise for this population of students when they realize that with the advent of their collegiate careers their personal care is now primarily their responsibility, where earlier in their educational journey family members typically handled that aspect of their lives. Building and establishing relationships with others who have physical disabilities can also be a developmental experience, just as building relationships with nondisabled students. Being able to build and maintain personal relationships with attendants and peers is a step-by-step process. And, establishing an identity, defining one's true self path, may be different for a SWPD using a wheelchair. Many factors can affect this vector, depending on how long they have had a disability, how long a person has been using a wheelchair, what the transition to college was like, and how they socially integrated. Discovering one's identity is a learning process which occurs gradually over time, with moments of success and failure (McCarthy, 2007). A large part of establishing identity for SWPD is tied to building self-advocacy skills (Hadley, 2011; Lynch & Gussel, 1996; Skinner, 1998).

This study also has theoretical underpinnings in Tinto's (1993) theory of institutional departure. Tinto's theory explains the longitudinal process of college students not returning to institutions of higher education, while capturing the complexity of behaviors that underlie that phenomenon. College students should positively separate, transition, and incorporate collegiate values as they become integrated into the academic and social systems of a college. During the transitional period, students depart from their communities at home and transition to college. To be successful, they must adjust academically and socially to the new environment. Students must assume personal responsibility to self-advocate for reasonable accommodations. As students transition to college, they begin to incorporate the values and norms of the college they are attending. Without proper accommodations, the transitions will be difficult. Multiple researchers have studied the usefulness of Tinto's model in predicting college student attrition (e.g., Cotton & Wilson, 2006; McKay & Estrella, 2008), and additional authors (e.g., Braxton et al., 2014; Braxton, Hirschy, & McClendon, 2004) have questioned the empirical backing of the theory and reworked issues associated with student departure.

College Students with Physical Disabilities Using Wheelchairs

Eleven percent of undergraduate students in the United States, over two million students, have a disability (Martin, 2012). Among all students with disabilities, the majority of the disabilities are not physically apparent; only 15% of students have orthopedic, or mobility, impairments. Among students with orthopedic impairments, 62% were found to have enrolled in college (Newman et al., 2011). College SWPD using wheelchairs have specific personal and academic needs while in college. People with dis-

abilities complete college at a significantly lower rate than those people without disabilities (Barber, 2012), suggesting that better academic and social integration supports may be needed for this population

The first year of college is an important time for students because it creates the foundation for subsequent educational experiences (Woosley & Miller, 2009). Students often express concerns over the transitional process, citing worries about interpersonal relationships, adjustment time, homesickness, and academic stress as potential obstacles when transitioning to an institution. The experiences found to be the most beneficial for SWPD in wheelchairs include enhanced academic and classroom experiences, a healthy and stable residential experience, and finding the right attendant care (Padgett, Johnson, & Pascarella, 2012).

Three-fourths of all United States college students leave at some point during their first year (Elkins, Braxton, & James, 2000). Therefore, it is important for colleges and universities to help students persist to the second year. Institutions have a variety of interventions aimed at the transitional phases, both during the summer before college begins and during the first few weeks of the semester (Woosley & Miller, 2009). There are many factors that help SWPD ease into the transition from high school to college: acknowledging strengths and areas of needs, learning about the disability services office, participating in precollege academics, taking responsibility for one's own education, and self-advocating are just a few (Connor, 2012).

The transition from high school to college can be overwhelming and confusing for many students. For SWPD, it is important to understand and articulate needs related to their disabilities (Hadley, 2011). Potential barriers to success can include "unawareness of the availability of academic support and reasonable accommodations, lack of skills in self-advocacy and self-determination, financial problems associated with paying for education in addition to disability-related expenses, inconsistencies in provision of educational supports" (Mamiseishvili & Koch, 2011, p. 93). These barriers can alter a student's transition to college in multiple ways. Students have to take initiative when it comes to attendant care. Trying to figure out finances related to attendant care, accepting responsibility for themselves for the first time, and being aware of campus resources are transitional issues which can affect students. Some students have Medicaid (United States social health care program) to cover the cost; others have Vocational Rehabilitation (enabling individuals with disabilities in the United States access to employment). "To improve chances for success in attaining independent living . . . the role of the attendant is necessary" (Atkins, Meyer, & Smith, 1982, p. 20). Students need to learn to take responsibility for attendant care (Birdwell & Fonosch, 1980). Setting up and maintaining attendant care influences students' well-being, as well as their academic success (Simon, 1977).

A common major issue with attendant care is that often students do not know the steps to take to locate the services they need and how to negotiate hiring an individual to serve in this role. Students may start by placing ads in newspapers, asking a friend if they would be willing to provide (paid or unpaid) help when needed, or find professional care through local agencies. Tiedemann (2012) discussed the need for students to figure out when they will need an attendant because the job is tailored to their schedule; the students need to know where they can go to locate an attendant to assist them. The time management issues for college students in need of attendant care may be a bit different than for others needing attendant care. These types of issues related to the specifics of student development experiences of SWPD using wheelchairs were determined by the authors to need further examination from the perspective of the SWPD.

Method

The purpose of this study was to explore the transitional attendant care issues and experiences of college SWPD who use wheelchairs. This study addressed the following research question: How do college SWPD using wheelchairs describe the issues they encountered and the experiences they had with attendant care as they transitioned into higher education?

Design of Study

In order to ascertain and better understand the perceptions SWPD using wheelchairs have about their transitions into college, specifically around their experiences with attendant care, this study used a qualitative phenomenological methodology in order to place a thick-description (Geertz, 1973) around the phenomenon under examination. This methodology was chosen because the researchers believe the transitional experiences of students with disabilities using wheelchairs, and who use attendant care, have collegiate experiences that are currently absent from the literature. Phenomenology helps organize a study when researchers are searching for "common meaning [shared by] several individuals of their lived experiences of a concept or phenomenon" (Creswell, 2013, p. 76). The lived experiences of college students with physical disabilities who use wheelchairs and have attendant care represent the experiential phenomenon un-

der examination. In-depth interviews were conducted by the first author to gain richly described and detailed explanations about the participants' transitions and experiences. A semi-structured interview protocol was used to best enable this type of data gathering where the interview questions are aimed at cognitive clarification of the participants' experiences (Kvale & Brinkmann, 2009). "The researcher relies on the participants' views as an inside emic perspective and reports them in verbatim quotes" (Creswell, 2013, p. 92).

The institutional context where the participants resided was a mid-sized public doctoral-granting residential institution located in the Midwest, which primarily serves undergraduate students along with some graduates (Carnegie Foundation, n.d.). The institution provides a disability services office to meet the needs of all students who identify as having a disability. There are also modified rooms (e.g., bedroom doors controlled by clickers, proxy cards to enter the residential hallway, accessible showers, and motion censored sinks) provided in the residence halls rooms accessible to students with disabilities. Many physical features of the buildings make them easily accessible to students with mobility limitations. To protect the confidentiality of the participants and the institution, the names and locations mentioned in the interviews were exchanged with pseudonyms during the transcription process.

Students who participated in this study self-identified as being an undergraduate with a physical disability using a wheelchair and having attendant care. The population was comprised of participants ranging from age 18 to 26. The participants had a variety of academic statuses (i.e., freshman, sophomore, junior, senior). Many had a diagnosis that required the usage of a wheelchair for independent living. Participants were not required to live on campus. No other delimiters (e.g., gender, disability type) were used.

Data Collection

A semi-structured interview protocol was used to assist with the data collection process. The purpose of the study, the related literature review, and the resulting research question were used to help build a direction for the interview guide. The interview guide was organized into two major sections: transitional issues and experiences the student had with attendant care. The participants were asked to be candid and share as much about their personal experiences and transitions as they felt comfortable. The interview environments were held in locations mutually agreed upon by both the first author and the participants. Participants were notified at the beginning of the interview that they would be asked some questions which were personal and sensitive in nature. The Institutional Review Board approved informed consent process was used. It is difficult for able-bodied persons to imagine instances where strangers would ask them to reveal normally private information about their health, bodies, or personal hygiene routines. On the contrary, a request of this nature would not be unusual for persons with physical disabilities (Braithwaite, 1991), yet it was still prudent to take extra care with the conversations prompted by the interview questions due to the sensitive nature of the topics under examination. Since some participants may have been hesitant to talk about such sensitive issues for inclusion within an academic study, thoughtful structuring of the interview experience was used to explain the purpose of the interview, and why the participants' responses would be beneficial to the study (Kvale, 1996). The researchers remained aware of the sensitivity level and took precautions to reassure the participants that the data collected would be handled with great care (Dickson-Swift, James, & Liamputtong, 2008). The participants were reassured that no one other than the researchers would have access to the recorded interview and transcriptions. The first author also explained that a pseudonym would be given to participants to ensure an increased level of confidentiality and in hopes to prepare them to open-up and fully engage in the interview.

A panel of experts experienced in the topic and/or qualitative research methodology reviewed the proposed interview guide (Davis, 1992) and provided feedback. The panel consisted of disability services educators and faculty members skilled in qualitative research. A pilot test, consisting of SWPD that were not a part of the study, was conducted by the researcher to refine and further develop the interview protocol, help frame questions, collect background information, and adapt research procedures (Creswell, 2013). Revisions were made to the interview protocol per the suggestions of the members the panel, and the results of the pilot test. At the beginning of the interview casual conversation was held to make the participant feel at ease and comfortable about the interview. The interview protocol consisted of questions that addressed background information (e.g., knowledge of attendant care prior to attending college), transitional issues (e.g., changes associated with attendant care while in college), and experiences with attendant care (e.g., having attendants other than family members, positive and negative experiences).

Data were collected during the fall semester of 2012 and spring semester of 2013. Purposive sampling and snowball sampling techniques were used to iden-

tify the sample. The director of the disability services office initially forwarded an email to the members of the target population. The email clearly stated that the participants were free to participate in this study, but their participation would have no influence on the services provided to them through the disability services office. Students receiving the email could then decide whether or not they wished to contact the first author and consent to an interview. Snowball sampling is asking a person who was interviewed if they could recommend anyone else who may meet the criteria to participate in the study (Bogdan & Biklen, 2007). These sampling techniques were used until the researchers determined, based on the ongoing data analysis processes, that phenomenological saturation was reached (Creswell, 2013).

At the beginning of each interview, the participants were notified that their participation was voluntary and that their identity would be confidential. Interviews did not have a set time limit, but were generally 30-60 minutes in length, and progressed until all questions from the interview protocol were asked. Participants were informed before the interview began that the researcher wanted to audio record the interview. Their permission was requested before recording took place. Participants were interviewed once.

The first 12 students who agreed to participate in this study comprised the sample, and all fit the inclusion/exclusion criteria of being an undergraduate with at least one physical disability, using a wheelchair, and utilizing attendant care. Participants had been diagnosed with various illnesses, including Muscular Dystrophy, Cerebral Palsy, spinal cord injuries, and bone diseases. Eight of the participants were male, and four were female; most students lived on campus. The majority of the participants were Caucasian, one student was African American, and another was of Pakistani descent. Participants' ages ranged from 18 to 26. Some of the students used wheelchairs from an early age; others began using them more recently because of illnesses. The first author was acquainted with some of the participants because of her role as a residence hall director. The second author has worked on other research related to students with physical disabilities, and the third author is a qualitative research methodologist who helped design the study and a former residence hall director who worked with students with physical disabilities using PCAs.

Data Analysis

Each interview was transcribed verbatim and verified by reviewing the transcripts against the audio recordings after the interview was conducted. The first author did all transcriptions. Coding of the transcripts involved aggregating the text into small categories of information; clusters of meanings were developed from significant statements and placed into themes (Creswell, 2013). This analysis technique resulted in systematic procedures that moved from a narrow unit, to more detailed descriptions of the phenomenon under examination. The transcriptions were cleaned by removing non-essential stutters, pauses, and/or filler words (Cameron, 2001). The descriptions were gathered and themes were identified and summarized to answer the central research question, how SWPD using wheelchairs described their experiences with attendant care as they transitioned into higher education. Memos, written reflections created by researchers, serve as a preliminary site of data analysis (Bogdan & Biklen, 2007), and were written by the first author and discussed weekly with the third author as the analysis took shape. The use of structured reflexivity exercises and prompts designed to elevate the analytical possibilities (Mulvihill & Swaminathan, 2012) were employed at all stages of the study to best equip the researchers with the insights needed to conduct an informed analysis.

Findings

The findings are divided into two sections, transitional issues for students with attendant care, and collegiate experience with attendant care. The dominant themes that emerged from the data analysis process are presented. We included quotations from participants to help explain major themes that were found. We did not select the "most articulate" interviewees, instead the most illustrative and representative aspects of the transcript data were selected as evidence to back up the interpretive claims we made in relation to the purpose of the study and the research questions.

Transitional Issues for Students with Attendant Care

The participants in the study had many specific experiences as it related to their transitions to college as a SWPD using a wheelchair and having attendant care. The mutual transitions that were discussed by the participants included time management, preparing for attendant care, training attendants, first feelings, accepting responsibility, parental involvement, and financial considerations.

Time management. Each participant discussed how time management played a factor in his or her transition from high school to college. Some of those issues included working with their attendants, getting

to class on time, and scheduling when they would do personal care tasks (e.g., restroom, shower).

For Jim-Bob, the transition to using attendant care was a major adjustment. He had never used attendant care, and previously had family members assist him.

> At first it was a lot slower than being at home with someone that had done it repeatedly for twenty years . . . I would basically have to plan my day around it . . . I feel like I spend most of my day sitting in my room waiting for my attendants to come in. If they are there and I'm not there within 10 minutes, they can just leave and I'm screwed out of them not showing up until the next one which is usually hours later.

Jane had similar experiences. "I've had to train my bladder to go when my aides come so that I don't have any issues. . . . I have to shower whenever it works for them." Being on a routine schedule with their attendants was a new experience for many of the participants. It was hard to transition from an environment in which your family members were constantly available to help when needed. Participants had to start relying on their attendants' schedules: going to the bathroom when they wanted was not an option. Everything had to be scheduled.

Participants also had mixed feelings about the flexibility of the aides from the agency that supplied personal attendants. Skylar said, "I had to time out when I would eat and when I would drink so I would know when I would be able to go to the bathroom." Biz and Steve used both an agency and private care (someone outside of an agency who serves as an attendant), and they had a great deal to say about their experience with agencies. Steve said, "you have to do everything on their schedule, so I would get up even on my days that I didn't have class. I would get up at like seven in the morning and I was just ticked off all the time." Biz stated, "you have to live your life on a schedule . . . I have to go to bed by a certain time . . . I felt like I was missing out on stuff and even on weekends." Not only did these students have to learn to manage time with their classes and other outside extracurricular activities, they also had to learn to schedule personal parts of their lives. Time management played a large role in their lives as college students.

Preparing for attendant care. Very few of the participants were prepared for what to expect from attendant care. A couple of them had a person assigned to assist them during high school, and a few more had attendants during the summers. Biz had attendant care in K-12. "At school they followed me around; they helped me take notes, go to the bathroom." Chad spoke of having someone help him put his books away during breaks, help him get food, and get things he could not reach. Jane said "My parents made me have attendant care just so we could get it set up my senior year of high school." Even though they had those experiences prior to college, they still felt like they were not prepared and had very little knowledge of what attendant care would be like in college. Chad said that when he first got started in college it was a "different world pretty much. . . . but it kind of helped me . . . it made me more specific on what I need help with, and it makes me understand myself as a person." Samantha, who had some attendant care during K-12, said, "I didn't know how it worked at all or how complicated it would be." Skylar said, "I didn't know anything about the hiring process, I didn't know how to pay for it. I didn't know a single thing."

However, there were two participants who were prepared for what they would encounter. Jim-Bob serves as a role model because he was ready.

> I am older and I realize, you know, that this is going to be my life regardless, so I might as well get used to it. If I had been younger, it would have been a lot harder to get used to it, but I think the maturity factor set in . . . so I was ready for all of that.

Training attendants. Participants spoke of their experiences regarding training their attendants to meet their needs. The process varied, depending on if they were going through an attendant care agency or if they were using private help. The choice to work with an agency started with the assumption that the attendants had some formal training regarding working with people who have limited mobility; when choosing to work with someone who does not work for an agency one assumed attendants had little training.

Skylar explained that her mother was with her and she trained the first attendant, but from that point on it was up to Skylar to do it.

> I had the stomach flu one time, and they sent someone new so I had to train them by myself with stomach flu. It is always really awkward saying like, "do this for me, do that for me," and sometimes I am a lot more independent than other people. So sometimes, they will do too much and sometimes they won't do enough, so it's kind of finding that balance.

Biz spoke of an agency that would often send different attendants. "I had to retrain everybody because they

have to lift me a certain way, and shower me a certain way." Chad had a very detailed way of training his aides. Years of experience had helped him advocate for himself. He serves as a best-practice for SWPD gaining experience of advocating for himself.

> Trying to explain what you need help with, like how specific you need to be or how discrete you need to be, I kind of feel it's my job to make sure that the aide is really comfortable . . . I said you need to meet me in my room, here are the things I need help with . . . getting up in the morning, putting me in the bed, this is how you lift me up, this is how you put me in my chair, this is how you help me use the restroom . . . you just really have to physically go through everything so that . . . everything is out in the open.

First feelings. Meeting someone for the first time can be somewhat awkward; meeting someone for the first time that is coming to help you take a shower can be completely uncomfortable. Participants spoke about first interactions with their attendants and how those interactions typically went. Samantha said that it was awkward at first because she knew that she would need a lot of personal care, "the first 5-10 minutes are really awkward, like 'Hi, I don't know you, you're going to help me shower,' that's awesome." When Skylar reflected on her initial experience, she noted that "It's definitely awkward at first because you're like okay, this isn't my family, but they're going to have to help me in the bathroom, they are going to help me shower, and it's, it's definitely humbling."

Charles, who did not have attendant care before coming to college, said that he thought he would be more apprehensive than he was. He shared that he was fortunate to get paired with an attendant whom he really liked. Most participants reported that the transition to attendant care was awkward, but something they had to accept as routine.

Accepting responsibility. Taking ownership of one's actions, and becoming fully responsible for one's self, is something most college students have to learn. Students realize family members are no longer there to get them up for to school, to make sure they go to class, and do homework. It becomes the student's responsibility to get things done. SWPD who use wheelchairs experience the same thing; however, they have the added responsibility of being responsible to advocate for themselves regarding their disabilities.

Participants talked about how responsibility factored in to their experiences with attendant care. Their responses ranged from enjoying this newfound responsibility, to being overwhelmed, nervous, and not feeling adequate. James said that it was unnerving at first because "I was afraid to make a mistake, to say the wrong things . . . It was kind of hard at first to do it on my own . . . I'm better at it now." He took a big step in accepting responsibility when he decided to switch agencies without consulting his parents. He knew that the first agency was not working out for him, and he made his own decision to switch. Both Biz and Skylar discussed how they knew they needed to be assertive, skills that prior to college they had not used very often. Skylar said, "it was overwhelming at first because I'm a boss to them, so that was weird to me because I am not very assertive." Chad thought about the responsibility as just being the first step to many he would have to take in life.

> It was a good feeling and you know obviously when you get out of college, find your own job, live on your own, you are going to have to do that anyway. I felt good about it, I just needed to realize what I needed help with, and just to voice that. Don't be scared to say what you need help with, always ask questions. . . . It helped me to be more mature and to be successful in college.

While everyone knew it was imperative that they accept responsibility, some struggled at first. Rebecca was the only participant to express that she had no major responsibility for her attendant care. Instead, her parents still continued to manage her care.

Parental involvement. Each participant mentioned that their family members, parents, and siblings helped them with their personal care before attending college. The level of parental involvement varied after the student started to attend college. Chad said,

> My parents didn't really know a lot about services I could use or anything like that so I think at the very beginning; I took it upon myself to find out information. . . . I need to have more focus on it than my parents . . . I had everything under control so they never really had any worries or anything. It was me looking for everything.

Skylar talked about her Mom's involvement when it came to her attendant care the first night in college. "My Mom stayed with me the first night to make sure I was able to speak for myself. She kind of wanted to see . . . who was going to be there." Skylar expressed that, as time went on, her Mom played a minor role in her attendant care. She knew who was helping Skylar, but she no longer helped with training the attendants.

Many of the participants said that their parents were the ones who picked the first agency to provide care. The participants stated that, over time, their parents had less of a role, and the majority of students eventually took the lead regarding their attendant care.

Financial considerations. Prior to coming to college participants had to figure out how attendant care was to be paid for. Options included Medicaid, Medicaid Waiver, Vocational Rehabilitation (Voc Rehab), or their parents paying the bill. These payment forms were combined or used singularly. These financial resources had differing requirements.

Charles spoke about how his Dad was very thorough and had prepared in advance for this transition.

> He got me on the Medicaid wait list about 10 years before I would need it, specifically because . . . the list is so long. He is forward thinking and he knew that . . . the time I got to college I would need that.

Skylar used Voc Rehab which stipulated the number of hours available per week. "They'll say you have this many hours to pay people. How do want to pay them? You can go through an agency, you can have private, or you can do both." Colton and Jane used a combination of both Medicaid and Medicaid waiver. Colton talked about not having enough hours for his attendant care through Medicaid, so he had to supplement it with Voc Rehab. "I have 24-hour attendant care, but I only got approved by Medicaid for 16 hours so it is kind of last minute thing to try and rush around to get Voc Rehab." Rebecca mentioned that her parents paid for her attendant care.

Collegiate Experiences with Attendant Care

The participants also spoke of many of their collegiate experiences relating to attendant care. They were new to the college life and, for most of them, their experiences with attendant care started from their transitions from high school to college. The mutual collegiate experiences that were discussed by the participants included attendant care preferences, relationships with attendants, supportive friends, and characteristics of attendants.

Attendant care preferences. Students had multiple preferences regarding the source of attendant care; some chose to use an attendant care agency because it better suited their needs. However, others chose to use private care and hired their own assistants.

Steve followed up on a list of current students which the disability services director had given to him.

> I thought for me that it would be more comfortable to have someone with a flexible schedule like me and we are all going to school here too, and can easily work with my schedule. . . . They are all around my age so you can kind of build a relationship with them easier than someone that is older.

Charles preferred an agency for his attendant care.

> I don't want students. . . . I don't want to have an attendant take care of me in the bathroom, or shower me, or wipe me after toileting business and then go out and see them working the desk here, or see them in my core classes that I have tomorrow, where we might be doing a group project together or something. That would be extremely awkward for me and I'm guessing that would be extremely awkward for them, because it is a personal measure of care.

Some students, for example Skylar, used both.

> As I got older, I became more involved on campus and I realized I couldn't function on the schedule that Agency A wanted . . . the latest that they will send somebody out is 10:00 pm and I knew that wasn't going to fly. . . . Sophomore year I hired my first full time out-of-agency person. . . . About junior year I started training my friends to help me.

Jane lamented that the difficulty with attendants was that you had to depend on them, and because of the way her daily life unfolded, it was not possible to always be so scheduled. With a rather realistic point of view, she said that "you are depending on people to help you do these things so you kind of have to work around them, so there is really no reliable attendant care."

Participants shared stories about their attendants. Biz ended up being taken advantage of by his attendants as they constantly showed up late, and sometimes smelled like smoke or were drunk. There was a time when the attendants came so late that he was unable to use the bathroom for hours, which lead to him having a urinary tract infection. Rebecca shared that her attendants were constantly late, and were incompetent; eventually it led to her getting sick, and having to temporarily leave school. She was very discouraged.

> I started commuting from home. . . . I didn't like commuting so I took the semester off to figure out if I really wanted to come back to campus to live. . . . Having such a bad experience the first time really scared me and my parents. We knew it couldn't happen again.

Relationships with attendants. Students tended to build personal relationships with their attendants, considering some of them as friends. Although Rebecca described her attendants as "caring, professional, and reliable," she viewed them as employees. "They are caring persons doing a job." James made it clear he preferred a more business-like relationship.

> I don't care about their personal lives. . . . I'm one of those people that like boom, boom, boom I have to get everything done so I can go. . . . I'm one of those people that tries to make sure people don't see I have aides that help me . . . for me an aide is there to work, not to play; they are there to help me.

Colton said "some of them are kind of friends, others . . . I just deal with them." Samantha had similar thoughts about her relationships with her attendants.

> Some of them I have actually become close with, we're friends kind of . . . we don't hang out outside of them helping me, but we talk. We are friends on Facebook, it's not completely professional. I have a couple of like older nurses that come and help me at night. . . . They have to help me, but we're not like friends.

It seemed that the younger attendants were viewed more as friends compared to older attendants with whom the relationships were more businesslike. Biz considered his attendants as friends that he looked up to; he felt they truly cared about him.

> I hold them to a higher respect. I considered them kind of my role models, when I need advice I talk to them, stuff like that, and especially people I have had for a long time because they know me.

Chad spoke about an experience where the actions of his attendant surprised him, and made him thankful for his attendant.

> One time me and my friends wanted to get off campus and I couldn't, they couldn't lift me in their vehicle so I called my aide and he said, "well I will drive you there and back." . . . He understood that I needed help, that I want to hang out with people and he's not like "I'm just here to help you, I'm not here to make your social life easier," so that really sticks out to me.

Although there were positive experiences, there also were negative ones. Jim-Bob had a situation with an aide who was not friendly and her actions actually led to his getting hurt.

> She was getting me out of bed one morning and the pump to pump my Hoyer that lifts me up in the air, my foot got stuck under the pump, and she pumped it anyway and broke my toe. When my toe broke I started yelling . . . her response was "well why was your foot there?"

Steve had an experience where his attendant was over two hours late. Because of that, he missed a test, a class, and was stuck in bed for a few hours because he had no way to get out.

Supportive friends. A number of the participants spoke of having friends who helped them when their aides were not available, and friends who understood and were not bothered by their attendant care. The participants spoke about how thankful they were to have those people in their lives.

James told a story about when his chair started malfunctioning and he was not near his building. So, he called one of his fraternity brothers who pushed him back to his room. Skylar's friends wanted her to be able to hang out later in the night, so they starting offering to help her get ready for bed.

> Billy came to me and said, "Why do you go to bed so early?" I was like, "I really don't." . . . At the time I had the agency come at 10 and help me get ready for bed. "I really don't, I just kind of lay there," and he's like "I can do that, that's not hard" . . . and he started helping me.

Biz's relationship with his friends went further than he expected. He had a less than desirable experience with agency care, and his friends started offering to help take care of him.

> I just decided to ask my friends if they would like to get paid to be my aide. I told them you will get paid for five hours a day, you don't have to be there the whole time, but I just need you to be ready to come over whenever I call you.

Sparky had a unique conversation with a professor who had mistaken his friend for his attendant.

> I had a professor . . . that came up to me and saw my friend helping me. He said "Well is this your friend/attendant or whatever" and he said, "Well do you get paid to do this?" The professor asked him that. He was like "Well, sir, to be honest with you I

> am doing this because I met Sparky freshman year, and he is a cool kid. I've always stayed in contact with him, and there is nothing that I wouldn't be comfortable helping him with. I've helped him off the floor of his shower when his attendants hadn't shown up; I've helped him go to the bathroom in an inaccessible spot. I've helped him, but you know I do that out of the goodness of my heart and not the fact that I'm getting paid to be his attendant." He was not getting paid to be my attendant; he was just my friend.

Characteristics of attendants. Many of the participants spoke about various characteristics of their attendants. Many of the females preferred to have female attendants. They were not opposed to males helping them as long as it was not in the shower, or to use the bathroom. The male participants had mixed responses. Some of them only preferred males to help them with showering and toileting, and some preferred females. It depended on the person and exactly what the attendant would be doing. There were some male participants who didn't care who helped them as long as they were getting the services they needed.

Some of the stereotypes the participants had were based on other people's perceptions of the attendants, as well as their own. Colton shared that many of the aids were the kind of people with whom he would not normally get along or want to be seen. James said,

> I know a lot of these aides come from backgrounds that are not as stable as mine, and they've got really good hearts. I know people that have the stereotypes, I have aides that have like weird tattoos and stuff like that, backgrounds where you can see their home environment is not the best, but their hearts are always in the right place. I just want people to know that even though they have a tough life and stuff like that, their only job is to help people in chairs and stuff like that. I just want to get that stereotype out because these people truly have big hearts, if they are willing to help me. . . . I mean there are some pretty private issues; they help me go to the bathroom, and help me go take a shower. A lot of people I don't know if they could do that.

Discussion

The theoretical frameworks that guided the data analysis centered on Chickering and Reisser's (1993) work related to identity development among college students, and on Tinto's (1993) work on academic/social integration as factors relating to persistence to graduation. Several of Chickering and Reisser's vectors were pinpointed as those closely related to the phenomenon under examination. The college students in this study described their development of intellectual and manual competence skills. Students began to develop a level of autonomy moving toward interdependence, but because they need to incorporate personal care assistance from others, the version of autonomy is different from that of an able-bodied student. The autonomous SWPD demonstrates their level of autonomy based on their ability and comfort with independently arranging for the care they need instead of relying on family and other systems to automatically take care of their needs. The participants in this study clearly described their processes of building interpersonal relationships with their peers, faculty members, staff, and personal attendants. Some of those relationships were easier to maintain than others. These participants reported learning about themselves during their transition to college and their related experiences with attendant care, therefore, further providing evidence that they were in the process of establishing identity as characterized by Chickering and Reisser's theory (1993).

In a related way, Tinto's (1993) focus on social and academic transition was also demonstrated in the descriptions the participants provided about their collegiate experiences as SWPD using wheelchairs and having attendant care. Some students thrived socially despite having attendant care throughout various times of the day and night; other students had a harder time achieving social integration. The transition to college is difficult enough for many students, but when transitioning as a student with a physical disability using a wheelchair and having attendant care, the social aspect can be somewhat harder to grasp initially. The same applies to their transition to the academic setting. Since there are no longer Individualized Education Programs (IEP) that accompany the students, the needed accommodations have to be taken care of by individual students. These students are responsible to request reasonable accommodations. If they do not advocate for themselves, the academic transition may be difficult.

Transitional Issues for Students with Disabilities Who had Attendant Care

There are many issues that arise as students transition to college. Attempting to balance and manage time during the first year of college is an important task for most students because they are creating the foundation for their subsequent experiences (Woosley & Miller, 2009). For SWPD, balancing time between academics,

social life, and daily living conditions can be stressful and challenging. As they arrive at college, many SWPD have to learn how to arrange for significant alterations in their daily schedules. For many SWPD, the transition did not always flow as smoothly as desired. SWPD must plan their daily schedules based upon when their attendants will be able to assist them. For many of them it seems as if they live their lives on a schedule tied to their personal attendant. These students have to make sure that an attendant is available as needed throughout the day, get to class on time, and find time to spend with their friends. When something happens in a student's social life, it can also affect their academic life; every part is tied together in some way. "Colleges like other human communities are highly interdependent, interactive systems in which events in any one part may be felt in other parts of the system" (Tinto, 1993, p. 108). When something happens with an attendant, a student's academic and/or social life has the potential of fluctuating. The experiences most beneficial for SWPD in wheelchairs included enhanced academic and classroom experiences, a healthy and stable residential experience, and finding the right attendant care (Padgett et al., 2012).

The students in this study had to schedule in advance common daily tasks that many people take for granted, such as timing for going to bed, getting out of bed, using the restroom, and showering. Scheduling these tasks adds complexity to the lives of these students. Scheduling for disability-related items is also probably true for students with non-apparent disabilities. Many college students find the transitional semester/year challenging (Mamiseishvili & Koch, 2011). In addition to routine transitional issues that all students must face, SWPD have the additional complexity of devising a daily schedule that includes when they interact with their personal attendants (Tiedemann, 2012). Variations in established schedules are problematic for these students, and may lead to a confounding factor of reluctance to socialize.

Preparing for attendant care, by someone other than their family members, was something many of these students postponed and had not carefully considered as a part of their transition to college. This delay is intriguing since attendant care is such an important part of their daily lives. More information about attendant care should be offered to students and their families before they get to college so that they can be better prepared (Tiedemann, 2012). In addition to having disability services staff hold workshops throughout the first semester to help the students prepare for potential attendant care transitions, pre-arrival programs may be helpful during the transition to college, and such programs should not be limited to a day or so before the beginning of the first semester (Elkins et al., 2000). Students need to be prepared for the challenges that attendant care will bring into their lives.

College students with disabilities must be able to self-advocate for their needs by discussing disability-related accommodations with their professors, faculty/staff members, and their attendants (Hadley, 2011; Lynch & Gussel, 1996; Skinner, 1998). Self-adovcation during training of an attendant is vital. Students with care provided through an agency do not have to worry as much about training because most often the agency provides attendants with some preparation. However the students who choose private care will need to spend time training their attendants. Self-advocacy regarding personal care is needed, meaning that a student understands his or her abilities and disabilities, is aware of the strengths and weaknesses resulting from the functional limitation imposed by the disability, and is able to articulate their need for physical assistance (Lynch & Gussel, 1996). The experience of training attendants can help students learn how to advocate for themselves in other ways.

College students must come to grips with accepting responsibility for a disability. Accepting responsibility means understanding the disability, speaking-up for yourself, and adequately explaining your disability and what it means for you as a college student (Connor, 2012). Once in college, the responsibility of self-advocating and explaining what is needed becomes the student's responsibility; parents' ability to speak for them is limited. Since the student is the primary person in control of decisions regarding personal attendant care, he/she should learn to effectively exhibit the qualities of a personal manager (Birdwell & Fonosch, 1980). After being in college for a while, most of the participants will attain some level of autonomy (Chickering & Reisser, 1993) through which they are able to handle their attendant care. Learning to be an effective consumer, by setting up and maintaining attendant care, will influence the students' well-being (Simon, 1977).

Prior to college, many parents of SWPD are an active advocate for their students (McCarthy, 2007). These parents are concerned about their students' safety along with the quality of attendant care being received. Most colleges do not get involved with employment issues of personal care attendants (Tiedemann, 2012); therefore, parents and students must find the appropriate care, often with little guidance from the college. Students should be made more aware of financial resources available to finance attendant care. It is important to request information about personal attendants from the college disability services office,

Vocational Rehabilitation, home health care agencies, and other students with disabilities (Mamiseishvili & Koch, 2011).

Collegiate Experiences of Students with Disabilities Who had Attendant Care

The source of attendants is an important decision for each student (Padgett, 2012). There are many factors that must be considered when decisions are made regarding how attendant care is managed (Atkins et al., 1982, para. 1). Deciding to use an agency that provides personal attendants is often a more practical path, because the student has less to do to make it happen. However, when private care is chosen, students have a larger role to play; the student must recruit potential attendants, interview, hire and train attendants, and develop a care schedule.

Forming strong relationships with others is in the best interest of students as they adjust to college (Chickering & Reisser, 1993). The way the students in this study viewed their relationships with attendants varied; some viewed attendants as friends with whom they wanted some kind of relationship, but others wanted a strictly business relationship. Some SWPD view their attendants as more than just an employee, desiring a friendship that requires additional time with their attendant, sharing common interests which lead to strong connections between the SWPD and the care giver. Students who prefer a business relationship with attendants will focus more on the attendant being there to help them, not necessarily on engaging in a relationship with them, keeping personal conversations to a minimum.

When transitioning to college, most new college students do not yet have an established network of friends (Chickering & Reisser, 1993; Tinto, 1993). It takes time for college students to find the people with whom they want to build relationships. Likewise, SWPD will need to work on developing friendships, with time building a solid group of friends who will be there for them throughout their collegiate experience. The relationships these students build are unique because, at times, their friends may also be in an attendant role.

Transitioning to college and building strong relationships with friends helps students engage in academic and social settings of college (Tinto, 1993), as well as becoming integrated into the cultural environment of the institution. Social integration with peers enables students, with and without disabilities, to better cope with the demands of the college environment. The support that SWPD receive from their friends will enrich their lives and help them succeed in college. Sometimes SWPD will have friends who will help them with personal issues such as getting in bed, or even using the restroom, when their attendants are not available. Having friends to help in these ways will be greatly appreciated.

Some college SWPD are not prepared adequately to interact with attendants (Tiedemann, 2012). Transitional issues related to attendant care may relate to the student's ability to manage time, train and interact with attendants, accept responsibility, deal with parental involvement, and make financial decisions. They need to learn to self-advocate (Hadley, 2011; Lynch & Gussel, 1996); they are the captain of their own ships, with few crewmembers around to assist them. Some college SWPD using wheelchairs are prepared for this experience, others are not. Understanding details about attendant care, and taking initiative, will help students to self-advocate and take personal responsibility. The relationships that SWPD have with their attendants will shape their collegiate experience. When the students have positive relationships with attendants, it influences their academics and social experiences; the same is true for negative experiences.

The personal characteristics that students possess when entering college (Tinto, 1993), and students' individual levels of commitment to an institution (Elkins et al., 2000), influence the transition of all college students. Although SWPD using wheelchairs and attendant care have experiences similar to many other students, they also have a set of experiences that is completely different from other first-year students. It is important to understand the unique challenges this subpopulation of college students face, and what they can do, and not do, to meet those challenges. SWPD that use a wheelchair, and will use attendant care, need to consider the implications of attendant care and plan ahead prior to beginning to attend college (Mamiseishvili & Koch, 2011). Knowing that attendant care will influence their collegiate experience, they need to better understand how to work with attendants. Being able to manage academics expectations, engage in a social life, and use attendant care is a challenge for new college students. Colleges and universities should consider what could be done to assist these students with their transitions to college and provide resources to help them be successful.

Recommendations and Limitations

A future study could look at the provider side of attendant care, interviewing the attendants about their observations of SWPD. This vantage point would also provide the attendants' views on the relationship they have with students. If the attendants are also college

students, the focus of the study could explore how their personal, social, and academic lives are influenced by their attending work.

Future researchers should consider adding a second round of interviews in which participants could reflect on the content of the first interview and provide additional information. The inclusion of focus groups may be beneficial to help participants consider common themes like if they received support, or advice from other SWPD.

Academic and student support educators should understand that students in wheelchairs utilizing attendant care are, in many regards, similar to other students entering college. How SWPD transition to college compared with students without disabilities would be an interesting subsequent study.

SWPD need to have a clear understanding of the role of campus disability offices. It may be helpful for the Disability Resouces and Services standard, associated with the Council for the Advancement of Standards in Higher Education (2013), to include a section on attendant care and best practices when working with students who utilize attendants. Educators should work to gain knowledge about this particular group of students in order to help with their transition to college. Specifically, residence life educators should focus on the development of best practices when working with SWPD using wheelchairs and their attendant care providers.

Better communication and relationships between staff in disability services offices and attendant care agencies should be established. This may be helpful as students consider the logistics of obtaining attendant care. By having an understanding of the services various agencies provide, the disability services office may be able to help students in preparing for the process when interviewing and choosing an agency

Future college SWPD that use wheelchairs should begin early researching attendant care options, potentially available to them through college disability services offices. Understanding personal needs, and being able to articulate them, will be helpful when students speak with disability services, as well as when choosing the form of attendant care best suited for them. These students need to have an informed understanding of the role attendant care will play in their lives. Preparing a list of potential questions to use to interview attendants and agencies would be helpful. They should self-advocate regarding what will be needed for them to have a successful college experience.

The topic involved sensitive aspects of participants' daily life; encouraging participants to share their experiences was occasionally difficult. Future researchers should consider ways to establish trust with the participants in order to increase student comfort and willingness to share personal information about their transitional issues and experiences with personal attendants. This was a single site study at a Midwestern doctoral institution. The information gathered from the 12 participants applies to their experiences only and is not necessarily the experiences of all SWPD.

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About the Authors

Nequel Burwell received her B.A. degree in psychology and communication from the University of North Carolina at Charlotte, and her M.A. in Student Affairs Administration in Higher Education from Ball State University. Her experience includes working in university housing; she also has interest in multicultural affairs, athletics, and disability services. She is currently a Hall Director in the Department of University Housing at the University of Tennessee. Nequel can be reached by email at nburwell@utk.edu.

Roger Wessel received his B.A. degree from Lee University and M.S. Ed. and Ph.D. in Higher Education from Southern Illinois University at Carbondale. His experience includes working in multiple student and academic support offices (i.e., enrollment, evaluation, career, orientation). He is currently a Professor of Higher Education in the Department of Educational Studies at Ball State University. His research focuses on the academic and social integration of undergraduates, specifically students with disabilities. Roger can be reached by email at rwessel@bsu.edu.

Thalia M. Mulvihill, Ph.D., received her B.A./B.S. dual degree in American Studies/Secondary Social Studies Education from Syracuse University and M.S. Ed. in Higher Education and Ph.D. in Cultural Foundations of Education from Syracuse University. Her experience includes working as a student affairs practitioner. She is currently a Professor of Higher Education and Social Foundations in the Department of Educational Studies at Ball State University. Her research focus on issues in higher education, qualitative research methods, innovative pedagogies, and history and sociology of higher education. She can be reached by email at: tmulvihi@bsu.edu.