

Transition to Adulthood: A Qualitative Case Study of the Lived Experience of a Young American Adolescent in Korea

Keywords: Transition to adulthood; LGS (epilepsy); Social and physical environment

Abstract

This qualitative case study was done to gain better understanding of the factors that contributed to the successful social participation and transition to adulthood of an American adolescent, named Addie, diagnosed with epilepsy. Addie's life chart was used to describe her experience of living with Lennox-Gastaut Syndrome (epilepsy). Major focus of the study was an exploration of her rich and positive experience of living in Korea, away from home, for 10 weeks. Analysis of Addie's lived experience in Korea revealed two factors that facilitated her independent living there, in contrast to her previous home life; 1) Social environment and 2) Physical environment and their subcategories. Following her return home from this experience, she was able to generalize the skills gained into her own environment in Los Angeles. The findings of this study indicate that the change in these two factors increased Addie's self-esteem, confidence, motivation and opportunities for participation in meaningful social interaction, thereby increasing her chance of successfully transitioning into adulthood.

Introduction

The transition to adulthood is a critical developmental process for young people [1]. Adolescence marks this transition period from childhood to adulthood, and is a complex and challenging time for all youth regardless of whether or not they have disabilities. "It is the process of moving from the protected life of a child to the autonomous and independent life of an adult. A large part of this process is acquiring fulfilling and meaningful daily occupations. Engagement in an occupation facilitates social engagement, skill development and feelings of connectedness and worth" [2]. During this period, youth with disabilities face the fundamental task of constructing a satisfactory life in the same way as their peers without disabilities. However, disabilities place greater challenges, making the transition even more difficult.

Especially for youth with disabilities, successful transition to adulthood is greatly affected by social participation and participation in age-appropriate activities which provide a sense of achievement and enjoyment during childhood and adolescence [3]. This participation is defined as engagement in everyday activities and situations by the World Health Organization's International Classification of Functioning, Disability and Health (ICF) [4]. Although adolescents with disabilities experience participation difficulties [3], it is through such occupational participation that they develop necessary skills and achieve health and well-being, gaining opportunities to develop a sense of belonging and identity [5].

Epilepsy is one of the most common neurological disorders in adolescents, with a taxing impact on activities of daily living. It



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has potential impact on health and well-being, participation, social functioning and ultimately, quality of life during adolescence and adulthood [6]. When seizures start between ages 2-5 and persist, they can evolve into the pattern of Lennox-Gastaut Syndrome (LGS), expressed as multiple seizures that include tonic seizures during sleep and continue lifelong [7]. Seizures can be controlled through adequate use of antiepileptic drugs in about 70% of individuals with epilepsy [8]. Regardless of the ability to control seizure activity, epilepsy has great impact on the lives of individuals affecting their participation, social functioning and successful transition to adulthood.

The aim of this qualitative case study was to 1) explore the lived experience of an American adolescent with LGS, who as a young adult lived in the Republic of Korea (Korea) for a period of time, and 2) gain an understanding of the factors that facilitated her successful participation and transition to adulthood.

Method

A qualitative case study methodology was used with the participant to 1) explore her unique experiences of living abroad in Korea away from her home in Los Angeles, California (CA), in the United States of America (USA), and 2) identify the factors that influenced her ability to live independently. The University Institutional Review Board granted approval for this study.

Participant

The researcher first met the participant, 18 months old Addie, in a therapist-client context at GxxCxx in 1998 and was Addie's occupational therapist for about 4 years. Social contact with Addie's family was maintained after Addie was discharged from occupational therapy and even after this researcher moved to Korea in 2011. After graduating high school in June 2015, Addie made a trip to Korea to visit her ex-therapist whom she has not seen for more than 10 years. She then returned to Korea to participate in a 10-week beginner Korean language program at IJ University in February 2016.

Addie had been diagnosed with Infantile Spasms at 17 months of age and the diagnosis was changed to LGS when she was 4 years old. She had seizure activities on and off until she was 10 years old, when they found that On fi (Clobazam) controlled her seizure. Although seizures were controlled through medication since 2006, by then Addie had already experienced developmental delays in speech, gross and fine motor activities, sensory processing, learning and social interactions. She attended special education up to high school. Addie was friendly and liked people but didn't have many friends throughout her American school life. Her few peer friends were from her special education schools. After high school, she was almost totally isolated, with no social network or support when she started community college.

Addie was very motivated, hardworking and self-disciplined. It was Addie who initiated and asked her parents if she could visit her ex-therapist in Korea. At that time, Addie and her family thought she would never be able to live independently away from her family and their support. Nevertheless, she enrolled in a 10-week language course in Korea and was able to live independently in a university dormitory setting. For further details of Addie's development history, please refer to the The Life Chart in the appendix.

Addie was chosen as the subject for this qualitative case study as she had a very unique experience of living abroad in a foreign country away from home [9]. The researcher observed the positive changes in Addie during her stay in Korea and asked Addie if she would be willing to participate in this study at the end of her 10-week language course. It seemed useful to explore factors which made it possible for an adolescent with developmental delays who thought she could never live independently to 1) live independently in a foreign country and 2) generalize the skills acquired there to transitioning to living independently in her own home environment. Addie consented to be the participant in this study as she is very proud of her achievements and wanted to share the information with others.

Data Collection

Data collection included semi-structured interviews, Addie's journal, email correspondence, observational notes and the researcher's reflective journal. Two interviews with Addie were conducted: the first interview was in Korea in 2016, after her 10-week Korean language class and the second was in Los Angeles in 2017, a year after her return home. To obtain another perspective, one interview with Addie's mother J, was conducted in 2017 after Addie's interview. The interviews were recorded on a mobile phone and transcribed verbatim. Addie kept a journal about her experiences in Korea in diary format. Addie's journal was reviewed and used for this research with Addie's permission. Detailed medical, developmental and occupational history was provided by J via email and coded in the form of a life chart.

The interview questions were designed to explore 1) Addie's experience of living in Korea compared to living in America in her own home environment and 2) how living in Korea influenced her participation in America when she went back. Some examples of beginning questions were: 1) What was your experience of Korea? 2) Do you think your life in Korea was different from life in America? In what ways was it different? 3) What was your experience of living alone, away from home and family? 4) What do you think made it

possible for you to live alone in Korea and how was it different from America? 5) Do you think you could have lived alone in America? 6) Is your life back in America different from what it was before visiting Korea?

Data triangulation included comparing interviews, Addie's journal, email correspondence and author notes [9]. The researcher maintained observational notes of Addie living in Korea and during the visit in her own environment in America as well as a self-reflective journal to address bias and present more objective perspective [10].

Data Analysis

Inductive thematic content analysis procedures outlined by [11] were employed. All transcripts of the interviews, Addie's journal, J's email and researcher notes were reviewed by the researcher and coded in a free textual analysis. An experienced occupational therapy research colleague provided peer debriefing during the coding and analysis stage of the research through discussions and reading researcher notes.

Member checking was used to establish trustworthiness [10]. The participant and her mother independently read and reviewed the transcripts and built on the list of factors. The emerging factors were then grouped together to form two factors with subcategories, each of which are related to successful experience, participation in the new culture, or living alone in Korea. Emerging factors were analyzed for connections and the interpretations made underpinned the development of higher-order factors that were given relevant titles and were compared with notes for verification [11].

Findings

Analysis of Addie's lived experience in Korea revealed two factors 1) Social environment and 2) Physical environment, and subcategories for each that facilitated living independently in Korea. Direct quotes from participants are provided to support, illustrate and explain the findings.

Factor 1: Social environment

Peer support

The first thing Addie mentioned in the interview about her experience in Korea is positive peer support. She perceived and described peers in Korea as "more welcoming, caring and incredibly social than American peers. They don't want you to get hurt, they truly express their compassion". This positive attitude from peers enabled Addie to reach out and make friends who were able to help her navigate her way around the university campus and the local places. She reported that "it feels really great to have a countless number of friends who really care and look out for you, unlike people in the States."

Safe, close-knit community

IJ University is located in a small city and both the students of the university and the local people tend to be friendlier than the people in a big city like Los Angeles or Seoul.

J appreciated the close-knit community at IJ University and thought it provided a safe environment for Addie to reach out to people. "The open friendly environment, the attitude of the students

towards Addie... emanated from the OT clinic, everyone from the person working at the bank to people in various guard stations, to even just the students.” She also mentioned “the fact that the language program had the same group of kids, in the same classrooms every day, provided so much more of a community than sort of passing from class to class and seeing those kids once a week... it’s a built-in community.”

Communication

Addie demonstrated speech delays in both receptive and expressive speech. In her home environment Addie got flustered and overwhelmed when communicating with people and felt awkward about asking people to slow down their speech to process the information. Her speech is slow and she felt uncomfortable talking to people in her own environment. However, J described communication as a factor that helped Addie feel at ease with Korean people. “There was a wonderful slowing down of communication and processing that happened... naturally... with people in Korea because of the language barrier... and so, while in United States... when Addie will ask a question and the answer comes back in this flurry of information, I feel like whoa... how can we... in a polite way ask for that information to come back in a bite-size chunk for Addie... but in Korea people checking for understanding... was part of the way they delivered information to her”. Addie also said “I just don’t feel like people need to classify me as ‘Oh Addie is special needs so she needs a note taker’ or you know, needing things to be repeated over constantly.”

Factor 2: Physical environment

On campus dormitory housing

Addie felt that “in order for someone like me to be independent, someone who I knew had to live close by me but when I went to Korea, I realized you know what? I can actually be independent on my own”. J explained that it was the dormitory experience that boosted Addie’s confidence. “In United States, the opportunities for kids who have learning challenges to experience college life are very limited and usually do not include campus living. There is apartment style assisted living but the assistance is way too much for what Addie would blossom under.” Living on campus in a safe environment with peers was just the right challenge for Addie to cope with.

Accessible geographical location & public transportation

J also felt the location of the campus was very accessible and safe for Addie. “Unlike Los Angeles which is very big city spread out and easy to feel overwhelmed, I think that the way IJ University’s campus is situated on a hill in a small city is particularly helpful in terms of not getting lost...I think it offers some really amazing geographical markers... that little town right there... has an up and a down... so easy to find your way around”. Addie confirmed this by saying “I would walk to my classes, from my dormitory which was English Town then I would meet up with a bunch of my friends. I usually walk down to meet them at a local coffee shop or restaurant right across from IJ. It feels safe to walk around.” This is very different to her home environment in Los Angeles where she cannot walk to coffee shops or to the local college. Addie also added that the efficient and reliable public transport system made it easy to get around, “sometimes my friends and I would take the train or bus to a certain area...

sometimes... I take a taxi... to the gym then a taxi back to IJ where I walk to my dorm. But I think it’s harder to find transportation in the US than in Korea”.

By Products of Lived Experience in Korea:

Effect of positive & negative peer interaction on self-image and self-perception

Addie expressed feeling “more comfortable meeting other people, new friends, than in the US.” She didn’t feel she fit in and she felt very isolated at the community college in the US. “When I first tried going to Glendale College, the thing I really noticed was that there are a lot of cliques. Most of the time at Glendale College, I’d be the girl either reading her books or doing her assignments alone at one of the tables at the Coffee Bean on campus while everybody was studying together, and not having a study person... it just felt weird ‘cuz it felt like a dark cloud.” Peers showed a negative attitude toward her and did not wait for her to process her thoughts or speech. Addie felt awkward and did not know how to ask people to slow down their speech.

In contrast, her peers in Korea made positive comments on how beautiful she was and she felt included and invited to be part of the college community. She felt she had created “a sisterhood... not such as a sorority thing but more of a sisterly friendship” with her roommate. “I don’t see myself as a special needs person anymore... I don’t have to feel different around my friends in Korea... making new friends really gave a boost and more of motivation to bring out the friendship skills of eventually asking them to hang out”.

Peer interactions influence self-esteem and sense of identity of adolescents with epilepsy [12]. It is evident through Addie’s experience that her self-esteem, perception and identity have improved through peer acceptance, close friendships, social inclusion and involvement. Addie’s identity as a special needs person has changed to one of a typical adolescent with peer acceptance.

Self-esteem, confidence and motivation

Addie summarizes her experience by saying “Korea is basically my second home which contains the refill tank of encouragement, motivation, self-awareness and just... all the amazing friendships and great experiences and the really good ways of knowing when to take on a really big challenge”.

Addie was able to establish a clear identity on campus “as a student at IJ. It feels a hundred times better cuz people, my OT friends and classmates, are constantly asking me, what are your plans after class?” She reported feeling “good to be included and be invited. Making new friends in Korea really gave a boost and more motivation to bring out friendship skills of eventually asking others to study with me”. Increased self-confidence allowed Addie to take “no” from friends without feeling awkward.

Addie had identified herself as a person with special needs who “wouldn’t be able to be independent like others. Four years ago, if you brought up the word ‘independence’, ‘living independently’ or even ‘college’, I would have just shut down and almost have a panic attack but when I went to Korea I realized, ‘You know what? I can actually be independent on my own.’ I guess it was just the bigger amount of confidence and motivation that emerged in me when I went to

Korea". Addie learnt that she doesn't "have to feel different around my friends in Korea."

Gaining autonomy & skills needed to live independently in her environment

J reported that Addie is now "taking care of every aspect of her life in her own environment in LA.... self-care, scheduling, laundry, banking, cabs, transportation, making plans to be out with friends. Remembering them, forgetting them... hahaha... not so often, communicating, managing her own schedule and her own sleep... having boundaries for what she could do and what she would decline". Living alone with a roommate in a dormitory on campus was the "just right" challenge for Addie to develop the necessary skills to live alone and participate and engage in everyday activities independently in her own environment.

Discussion

The results of this exploratory study demonstrates that an adolescent with learning challenges due to LGS gained independence and learned to live independently within a relatively brief period (10 weeks) in a supportive social and physical environment. The skills she gained in the new environment were sufficient enough to generalize in her own home environment where she had never thought she could transition to living independently in adulthood. The outcomes reflected that Addie experienced positive change in her social and occupational participation and improvement in her self-esteem and confidence.

The findings from this study revealed two factors, 1) Social and 2) Physical environment, which facilitated independent living. These findings are consistent with those of [1] study that important "helping" factors in the transition process include friendships, social life, work and independent housing. For Addie, building positive friendships and social life in Korea were definitely facilitators in developing the skills needed for social participation back at home in the US.

According to [13], the limitations to social occupations are multidimensional for adolescents with epilepsy including "cognitive-developmental level of adolescents, issues with language development and communication, issues with efficacy based on past experiences of negative attitudes from others, or restrictions on in meaningful activities leading to social isolation from peers" (p. 96). Communication and negative attitudes from peers were definitely identified as barriers to Addie's social participation including "feeling awkward" around peers who did not have an understanding of her challenges and so excluded her from their cliques in the US. At that time Addie had not yet developed the strategies for how to self-advocate and ask for needed accommodations in America and felt very isolated and left out. However, in contrast to her interactions in the US, Addie's slow processing in receptive and expressive speech and language facilitated her interactions with her Korean peers who wanted to practice their English with her. Therefore, the communication and the negative attitudes from peers resolved naturally for Addie in a non-English speaking country due to the language barrier.

According to Park [14] Korean students show a preference for American English (verses British English) and have a positive attitude toward Americans, perceiving "Americans as cool, open and friendly

people" (p. 25). This positive attitude towards Addie, "the American", was demonstrated by Korean students who were very enthusiastic about interacting with her, boosting her self-esteem and confidence, making her feel accepted by her peers.

Although [7] reported that "almost all persons diagnosed with LGS have an intellectual disability that precludes independent living; they will always need someone to help them with activities of daily living, finances, recreation, and access to health care, and many end up in residential living arrangements" (p. 27) this study demonstrated that independent living is possible with appropriate physical and social environmental support. Addie was diagnosed with LGS and related developmental delays, which made her and her family think that she could never live independently especially in her own community where "there are few housing options, poor accessibility and limited transportation" [15]. But because IJ University's introductory Korean language program for foreign students allowed Addie to live in a dormitory on campus with a roommate, Addie was able to take on the challenge of living away from her family. J felt assisted living was too much help for Addie whereas living in a dormitory with a peer roommate was a "just right" challenge or "an optimal fit" [16] between the demands of the occupation and Addie's skills. Along with having a roommate, J felt the close-knit community on campus proved to be a safe environment for Addie to interact with people comfortably.

During the 10 weeks of the language program in Korea, Addie was provided with "opportunities to practice independent living skills, develop routines to support employment, housing, and education [17] in a safe and friendly environment. These successful opportunities boosted Addie's self-esteem and confidence in her abilities and no longer stop her from interacting with her peers at the community college she attends or independently participating in her daily occupations including self-care, laundry, arranging transportation and shopping back in the USA. Successful engagement in meaningful occupations in Korea motivated her to rebuild her sense of self to participate in her own community.

Clinical Implications

"Transition from late adolescence (16-18 years of age) to early adulthood (19-25 years of age) is a challenging time as adolescents leave the familiarity and support of their families and school systems and enter adulthood. Transition can be even more challenging for young adults with disabilities who depend on the support and routine of their families, school, and community services" [18]. More and more adolescents with disabilities are now entering adulthood compared to 20 years ago, "leaving many of these young people and their families ill-equipped to navigate the adult system to attain the developmental goals while coping with the fragile nature of their conditions" [19-21].

Addie was one of these many adolescents transitioning to adulthood not prepared to navigate the adult system in her own environment. She was very fortunate to travel and find an environment that provided opportunities to gain skills needed for independence. Not many adolescents with or without disabilities have the opportunity to travel to find an environment that provides them the opportunities to develop the necessary skills for social and occupational participation. Therefore, the results of this study cannot be generalized to all

families with adolescents and young adults with disabilities. However educators and occupational therapy service providers that works with adolescents with disabilities may take into consideration the findings of this study regarding the social and physical environmental factors when they facilitate the transition planning and process. They can tailor those factors specific to their own community to find the best social and physical environments that facilitate transition and participation in independent occupational performance. Also providing opportunities to develop independent living skills through experiential learning in a safe environment would be beneficial.

Many researches on adolescent transitioning to date are about transition process, planning or the role of therapists in transitioning. There are not many studies about the actual transitioning intervention or experiences of the people with disabilities. Stewart et al. [22-25] also reported “there has been less written about environmental factors such as physical, social, cultural, institutional/systemic and/or societal factors” that influenced transition process. Further studies looking at the transitioning experiences of adolescents with disabilities would be helpful in gaining a better understanding of the factors that influence transitioning.

In addition, the researcher was also the participant’s ex-therapist which could bias the findings. Yet, having observed the participant over many years the researcher may have a deeper appreciation of her development of the skills needed for transition.

Conclusion

This study demonstrates successful transition to adulthood of an adolescent with learning challenges due to LGS within a relatively brief period (10 weeks) in a supportive social and physical environment. Healthcare providers working with adolescents transitioning into adulthood and into community should look at the physical and social environmental factors to facilitate smooth transition.

The author wished to close this paper with Addie’s parting words which reflect the positive change in Addie and her desire to see more people with disabilities to successfully participate in adult life: “I really want to pass that same amount of encouragement, effort and motivation on to children with disabilities and their families so their child can eventually succeed in their world when they enter the real world in their teens or in their young adulthood. I don’t want them to feel like they are different from others”.

Competing Interests

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