

Life management of post-secondary students with disabilities

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The paper constitutes an examination of life management of post-secondary students with disabilities. Eight individuals, all in attendance at a Western-Canadian university, were interviewed. The purpose was to explore life management issues and transformational outcomes of living with a disability as reported by individuals with disabilities; and whether these are, in any way, comparable to issues and transformational outcomes reported by parents living with children who have disabilities. Scorgie, Wilgosh, and McDonald (1996) had identified nine themes, through in-depth interviews, related to parent effective life management strategies, personal qualities, and transformational outcomes from parenting children with disabilities. For the post-secondary students, thematic analysis of the interview data yielded five life-management themes, one related directly to transformational outcomes of living with disabilities.

The focus of the paper is on life management and transformational outcomes reported by post-secondary students with disabilities. To this end, individual interviews were conducted with eight students in post-secondary programs of study, thus providing the content for the relevant thematic analysis.

We have been conducting research for over 10 years on parent effective life management when a child has a disability. Over that time we have identified and extended our understanding of nine themes related to parent effective life management, originally identified through a qualitative/interview study (Scorgie, Wilgosh, & McDonald, 1996), with themes covering parent effective life management strategies, personal qualities, and transformational outcomes from parenting children with

disabilities. These themes have been corroborated over four survey studies using the Life Management Survey (LMS) with parents of children over a range of ages and disabilities, in Canada (Scorgie, Wilgosh, & McDonald, 1997; Wilgosh, Scorgie, & Fleming, 2000) and cross-nationally in Italy (Nota, Soresi, Ferrarai, Wilgosh, & Scorgie, 2003; Wilgosh, Nota, Scorgie, & Soresi, 2004). In addition, we have continued our qualitative research longitudinally and cross-culturally, developing a model of the parent transformational process (e.g., Scorgie, Wilgosh, & Sobsey, 2004), based on parents' reports of how they have been transformed as parents of a child with a disability. As a next stage in the research, it seems reasonable to explore whether our model of the parent transformational process might have any application to the lives of individuals with disabilities.

Examination of how people manage stress has found many reports of positive outcomes as a result of experiencing traumatically stressful events (e.g., Barnard, 1994; Janoff-Bulman, 1992), indicating that individuals have actually benefitted from extremely difficult, even devastating life events. Certainly, parents have reported being devastated initially, on learning that their child has a disability (e.g., Green, 2001; Scorgie, Wilgosh, & McDonald, 1996), and individuals who have experienced such traumatic injuries as spinal cord injury (SCI) have reported strong feelings of devastation (Sloan & Wilgosh, 2005). However, one cannot assume that such events lead directly and necessarily to solely negative outcomes. Aldwin (1994) proposed that stressful life events require new ways of thinking and acting; "rather than simply a homeostatic function, the more important role of coping may be transformation" (p. 270).

Many parents have reported (e.g., Green, 2002; Kearney & Griffin, 2001) positive experiences as a result of parenting a child with a disability. Researchers are also beginning to more formally document such positive changes. To illustrate, Scorgie et al. (1996) reported parent experiences of profound personal, relational, and perspectival changes, directly attributed by the parents to parenting a child with disabilities. These findings have been consistent in the Scorgie et al. research data over the past decade with over 200 families in Canada, the US, and Italy,

regardless of the age or disability of the child (e.g., Wilgosh, Nota, Scorgie, & Soresi, 2004).

Similarly, caregivers have reported that working with individuals with disabilities has resulted in profound personal transformations. L'Arche, a worldwide network of communities of people with developmental disabilities living with others, is based on a relationship between people with disabilities and their assistants, nurturing and celebrating each individual's unique characteristics and gifts. "Leaders of the L'Arche communities often talk about *transformation* as something that happens in equal measure to members with and without disabilities" (Biersdorff, 2002, p. 7).

Perceived quality of life has been linked to adaptation and positive outcome in research with persons with disabilities. For example, in a study of 98 adults with multiple sclerosis (MS), Bishop, Stenhoff, and Shepard (2007) found that, despite fatigue and limitations of MS, many respondents reported high perceived quality of life and well-being, suggesting that quality of life is highly individualized and related to the perceived limitations of MS on domain areas that are important to the individual. Furthermore, individuals with high quality of life were able to make appropriate goal modifications or substitutions that enabled them to accomplish valued life objectives. Bishop et al. suggested that high perceived quality of life serves an adaptive function to combat the difficulties of coping with chronic illnesses. Similarly, in a study of 165 veterans with SCI, Rintala, Robinson-Whelen, and Matamoros (2005) found that perceived quality of life was positively related to the existence of effective social support systems and negatively related to the experience of financial difficulties and physical limitations.

Finding personal meaning or positive outcome in situations of loss is associated with adaptation and resilience (Boss & Couden, 2002). Paterson, Thorne, Crawford, and Tarko (1999) found, for individuals with Type I diabetes, that positive transformational outcomes, including an enhanced sense of self and personal mastery, were related to individuals' positive outcomes. Such positive transformational outcomes have also been reported of persons with HIV, who identified a

heightened sensitivity to life and desire to be of service to others (Courtenay, Merriam, & Reeves, 2000); and women with breast cancer, who demonstrated increased measures of self-esteem and well-being compared to control group women (Carpenter, Brockopp, & Andrykowski, 1999). Taylor (2000) reported life-changing statements from women with breast cancer, to the effect that they had become better persons or gained in wisdom from the breast cancer experience.

In a study of accident victims with paraplegia, Czikszenmihalyi (1990, cited in Bowman, 1999) reported that many participants claimed that the accident was one of the most negative and most positive experiences in their lives. Accident victims described both detrimental and beneficial outcomes that were directly related to their experiences. Berge and Holm (2007) purported that such "dialectical thinking," or the ability to hold two opposing views of a situation simultaneously, enables people who have experienced loss to remain both realistic and hopeful.

Transformational outcomes of people with SCI have been addressed in the literature, with transformation characterized as a dynamic, cyclical process that changes over time and is never over (Hansen, Buckelew, Hewett, & O'Neal, 1993; Sloan & Wilgosh, 2005; Winneman, Durand, & McCulloch, 1994). Sloan and Wilgosh (2005) reported some similarities between the personal, perspectival, and relational transformations reported by participants with SCI and the parents of children with disabilities, in managing life effectively under stressful life circumstances. However, it is important not to draw hasty or definitive conclusions because of the apparent similarities in parent and participant reports. The authors caution that people with disabilities and parents of individuals with disabilities are not homogeneous groups and that each transformational experience occurs within a different contextual environment, thus making it difficult to generalize results. Further research is warranted, i.e., perspectival, relational and personal transformations warrant further exploration, both for individuals with SCI or other life-changing disabilities, as well as for parents of children with disabilities.

Based on the growing evidence, from research and personal reports, of

positive transformational outcomes for parents and others who have provided care for someone with a disability, as well as the growing evidence of positive transformational outcomes reported by individuals with disabilities (e.g., SCI), it is reasonable to explore further the nature of the transformational outcomes reported by post-secondary students with disabilities, and to assess the extent to which such reports fit with the types of transformational life changes reported by parents and caregivers, i.e., personal (changes in who I am), relational (changes in how I relate to others), and perspectival (changes in how I view life) (Scorgie et al., 1996). Therefore, the purpose of this study was to examine the personal reports of post-secondary students with disabilities, for life management issues and indications of positive personal, relational, and perspectival transformational outcomes.

Procedures

The purpose of the study was to examine life management of individuals with disabilities in attendance at a Western-Canadian university. After ethical approval for the study had been obtained from the university, notices were posted in suitable places across campus in order to contact individuals who might be willing to participate in an personal interview of one to two hours duration, to discuss how their disability has affected their lives. Potential participants made telephone contact and were informed of the interview purpose, that their personal information would be kept confidential, that they would be interviewed using a pseudonym of their choosing, that they would be able to withdraw from the study at any time should they choose to do so, and that a referral for counselling or other support would be available should they require such assistance during the interview or follow-up process.

Eight individuals chose to participate in the interview process. (A ninth volunteer was not included due to prior contact with one of the researchers.) The participants were interviewed in a convenient location of their choosing, and the interviews were audio-taped for subsequent transcription. The interview format involved (1) explanation of the study, further to the explanation provided in the initial telephone contact; (2) initial collection of demographic information, such as age,

nature and time of onset of disability, program of studies, career interests and goals; (3) a focus on the main question: "Please tell me, in as much detail as feels appropriate and in whatever order fits for you, how disability has or has not changed or transformed your life;" (4) subsequent questions or prompts served to draw out more detail (e.g., how has disability affected/not affected who you are, and what strategies, qualities, and supports have helped your management of disability).

After data transcription, a thematic analysis (e.g., Scorgie et al., 1996) of the interviews yielded five themes, as outlined in the next section of the paper.

Results and Discussion

As a first step in discussion of the interview data, a description of the eight interviewees is presented, excluding information that would compromise their individual identities. All names are pseudonyms chosen by the participants. "Tia" (LD) was diagnosed with a learning disability in comprehension and math/reading problems in adolescence. She is in a general undergraduate program of studies, with a goal of doing graduate and professional studies. "Jean" (LD/ADD) was diagnosed, about two years prior to the interview, with a mild learning disability in auditory processing and reading and attention deficit, after a professor suggested she seek assessment for learning difficulties. She is in a general undergraduate program, with a goal of graduate studies. "Anne" (Lup) recently acquired Lupus; she is currently working on a graduate program of study. "Smart" (male) (JRA) was diagnosed with juvenile rheumatoid arthritis, was symptom free for about 15 years, and now deals with symptoms of his illness while studying in a university undergraduate program. "David" (CP) has had cerebral palsy from birth, uses a mobility aid, and is in an undergraduate program of studies. "Elizabeth" (LD), after struggling through her basic educational studies, was diagnosed as a university undergraduate, with a verbal learning disability, mostly in the area of math and memory. "Shakespeare" (female) (PPS) has been diagnosed with post-polio syndrome, is married with children, uses a mobility aide, and is currently in an undergraduate

program of studies. "Sue" (blind), the eighth interviewee, has had a loss of sight, a challenge in her undergraduate program of studies. In summary, six women and two men were interviewed, ranging in age from the early twenties to forties, with a range of disabilities (three with learning disabilities, and five with physical disabilities), and with a range of age of onset (from birth to recent onset).

The following five themes emerged from the interview data, discussed within the lives of the participants, with no attempt to establish order or degree of importance. To assume that a theme common to a greater number of participants in a more important theme would risk devaluing a theme which may be of primary importance to only one participant.

Theme I: Pre-diagnosis and Diagnosis Issues.

Four individuals talked about the time before diagnosis and the impact of being given a diagnosis of a disability.

I a: Low Self-esteem/Expectations. Three individuals (all with LD) reported having low self-esteem prior to diagnosis. They reported feelings of little worth. Elizabeth (LD) reported that she did "very poorly" in a university transfer program; "I was working very hard at it and I wasn't getting good grades at all." Her family also had low expectations for her, reinforcing her low self-esteem: "The family didn't have much hope for me being anything other than a waitress... they just could not believe I was university material." When being assessed for learning difficulties, Elizabeth "thought that I was really wasting the tester's time... I was not going to go back to them and ask questions or anything." Jean (LD/ADD) had very low self-expectations. She would make a joke about her low achievement before any one else did: "I'd rather... insult myself and call myself 'dumb' than someone else so I... beat them to the punch." Jean reported defaulting to a lot of non-academic courses which, she now feels, held her back academically. Tia (LD) reported low global self-efficacy, had no goals, hopes or dreams, and would have dropped out of school without a diagnosis. "I just thought I was an idiot... everything was going pretty downhill for me... When you don't feel that you're capable of anything, you don't have big aspirations for yourself..."

I didn't even have goals."

I b: Negative Feelings Pre- and Following Diagnosis. Individuals reported negative feelings and thoughts. Elizabeth (LD) reported self-destructive behaviours: "I started drinking and other things... I didn't really show that I was motivated towards anything other than self-destructive behaviours." Elizabeth found the assessment report and diagnosis devastating: "It (the report) focused on how 'below average' I scored on all of the subtests. I found it to be very cold and negative... So I had to believe I was stupid, that now it was on paper." Anne (Lup) reported on her diagnosis of Lupus: "When I was told, it was devastating." She reported struggling with depression, and with stress from the Lupus disease. Jean (LD/ADD) reported that the diagnosis affected all aspects of life: "Sometimes frustration level would be there and I wouldn't know why... sometimes you tend to be quite reactive to situations... hypersensitive... It has obviously impacted on my entire life."

1 c: Effect of Labeling and Disclosure Issues. Elizabeth (LD) reported using the label as an excuse initially: "I used my label as a crutch... I used my disability to explain my low grades and as an excuse to not work as hard. Why bother? It was not something that sounded like it could be 'fixed.'" Her feelings about the label were: "It was almost like I was harbouring this dirty little secret... feeling almost ashamed, actually." Similarly, Anne (Lup) tends not to reveal the pain she experiences, tends to associate with friends who have the same physical status, and only reveals her illness to friends with whom she feels safe: "I don't talk of my problems with somebody I don't know. There are only two friends of mine who know in the class... they are real friends; because we have been taking open studies together I had to tell them about me and that's how I am feeling and keep quiet... the class doesn't know..."

Jean (LD/ADD) reported that the label was disconcerting at first, and she struggled with disclosure issues: "Having a label... it's a bit disconcerting... the word 'disability'... it's now going through the next little while or for the rest of my life... being a little cautious as to who you tell and how you tell it..."

1 d: Having a Diagnosis has Raised Hopes. Both Elizabeth (LD) and Tia (LD) indicated that the diagnosis raised their hopes. Elizabeth stated, "I did take small comfort in the knowledge that maybe I wasn't stupid, or maybe I wasn't as stupid as I thought I was." Tia reported, "When I first found out about my disability, everything kind of made sense... totally changed my life."

Jean (LD/ADD) commented that, having a diagnosis, her disability is starting to make sense to her and shedding new light on unanswered questions. "It's kind of always been there but I've coped with it for a long time and now it's starting to make sense... it also gave me a bit more insight and did answer a lot of those questions... now I can step back and do things a little differently than before so things don't have to be so frustrating."

In summary, particularly for the LD participants, the pre-diagnosis and diagnosis periods had substantial negative aspects, feelings of low self-esteem, depression, and little worth, followed by further negative feelings of frustration following diagnosis. Being labeled was a negative experience, initially, with reluctance to disclose the diagnosis to others. Finally, there was a growing sense of hope, that they might have more capabilities than they had previously believed. While Anne (Lup) shared some similar experiences, it may be that this theme has particular impact for those with LD; this warrants further exploration.

Theme II: The Challenges of Disability (Negative and Positive).

Disability challenges of a negative nature tended to dominate the participants' stories, although there were strong positive challenges as well.

II a: Negative Challenges of Disability. Sue (blind) reported that her disability has narrowed the scope of her educational and career possibilities, as well as her friendship base. Shakespeare (PPS) has found her disability to be hard on family; they and others may tend to deliberately misrepresent the seriousness of the condition so as not to worry her. "I'd say to my husband, 'You know I'm getting worse than

what I was before,' and he'd say, 'No, no, no, no, you're not...' and I'd say the same thing to the arthritis specialist and she'd say, 'No, no, no, no, you're not,' and I knew fully well I was..." She also commented on loss of friendships, due to being too tired for activities; "I'm just too tired to go to choir..." She noted that her mental functioning and memory were affected; and that she experienced fatigue, frustration, and physical limitations ("... my body is not as strong as it used to be and gets tired much quicker... I struggle with getting my grammar correct... and I cannot do maths... So long as I watch what I'm doing it's not so bad"). Elizabeth, as did Shakespeare, reported resigned acceptance; "I just have to accept it and try to live with it and deal with it... It's really not that bad."

As did the other participants, David (CP) reported that he had to find out who his true friends were; "You see the side of people that just doesn't want to deal with anything... when they're confronted with a person who's different... or you see a side of people that it really makes them think about... what they can do to be helpful... really find out who our real friends are." Smart (JRA) reported many negative challenges, changes to his social life, loss of his active athletic life and peer support group; "Those people that you go forward with aren't there any more." He had feelings of being pushed aside because he couldn't participate in sport and other friendship activities. A big concern was poverty; "And then there's the poverty aspect of being disabled... I'm on AISH (assisted living support) so there's not a lot of discretionary income." He stated that everything revolves around how you feel; "You wake up and hope for a good day."

Anne (Lup) believes that pain has affected the way she thinks, her short concentration, lack of physical energy, "... and it brings a lot of depression." Pain has curtailed her social life and friendships with people who don't understand. "I've seen how it is cutting off friendship from others." Also her disease and related disability have resulted in financial problems: "Of course, financial problems will hit... I can't now do a full time job... so that's part to do with the financial." For Jean (LD/ADD), the fact that LD is an invisible disability creates awkward situations, for example, "They say, 'Well, you look fine...' Society does..."

tend to want to focus more on bad things..." She finds that she is oversensitive about things and this can be debilitating; "Am I starting to use it as a crutch... because I don't want to do that." Tia (LD) reported a negative challenge being in an LD class; "There was a lot of stigma that I was in an LD class."

All of the participants dealt with significant negative challenges, from loss of friendships, to effects on academic performance, physical and emotional stamina. Three participants mentioned financial hardship as a result of disability, directly or as a result of reduced occupational options.

II b: Positive Challenges of Disability. Many of the participants identified challenges as positive aspects of disability. Sue (blind) reported that a strong positive challenge is the challenge to be independent. She has encountered blind individuals who are dependent, "... and I've decided I don't want to be like them." Elizabeth reported many positive challenges and fewer negative challenges, that disability changed her life for the better ("I think it's shaped me very positively"), and helped her to recognize her personal qualities ("It's made me see what my strengths are"). David (CP) reported positive challenges having to break social barriers of pre-conceptions to make social contacts; "I'm always the one who has to introduce myself as someone who is completely intelligent... to break that barrier (of preconceptions) and that's always created a challenge because it means that I have to be outgoing which I'm not..." Smart (JRA) views education as a way to get out of assisted living and poverty; "I could do that (stay on AISH) and be miserable and poor, or I could do something about it. And I'm trying to do something about it." Jean (LD/ADD) reported that she has made a conscious effort not to make the disability an excuse. She stated she must learn to treat herself better as she learns to manage her disability; "I must learn to treat myself as well as I treat others, to give myself a bit of a break..." Tia (LD) has learned to treat herself better and take a positive approach. "I could have looked at it as a ... very negative thing... but I approached it as a positive thing."

Many challenge-related strengths will be reported under Theme V, as

transformational outcomes of disability.

Theme III: Feelings Toward Disability/Identity Issues.

While there is overlap with other themes, there were distinctive feelings expressed by participants related to their disability, as well as identity issues. Seven of the eight participants indicated that the disability is a part of their identity or their life, while one reported that the disability is not a part of her.

Sue (blind) doesn't feel that her disability is a part of her identity ("I never describe myself as a person who is blind or visually impaired") and doesn't want to be distinguished as a person with a disability. She reports feelings of discomfort toward her disability ("I think I'm embarrassed of it a bit..."). Her parents, relatives, and close friends don't treat her differently and she is trying to be the same person and not let the disability make a difference ("I just try to function normally and do what everyone else does and try to be the same person"). She believes she is significantly different from congenitally blind individuals; "Their perspective on the world and the way things run is just different."

Shakespeare (PPS) believes that the disability is a part of her; "It's very much a part of me, yes... it's not incidental." She also expressed embarrassment about her disability and dresses to avoid drawing attention to her disability. Loss of physical and motor abilities has affected her identity and her inability to do family and household duties has led to alteration of family relations ("... I'd be stuck in bed and my husband would have to even drive me..."). She is learning to pace herself and adapt to her limitations ("... so long as I do things in small quantities and not over-stretch myself..."). Elizabeth (LD) declares that she owns her disabilities but is not defined by them. "I see it as a part of who I am... definitely my learning disability is a part of that."

David (CP) commented that disability is "a part of [his] life, like it to be or not;" but it is important "to get out there and experience the world as much as everybody else does." Smart (JRA) also believes that disability is part of him and he has to deal with it ("sometimes you know it's a part

of you because there's pain"); he has to schedule life around pain and it interferes with his socialization, and has resulted in loss of friends. He dislikes dependence on others for his needs; "I hate having to rely on these people (e.g., disability services)." Because he doesn't look disabled, he indicated that he is made to feel he doesn't deserve services: "And then they look at me and, 'Well, maybe he doesn't need... is he disabled enough to... ?'" He also tends to pass on services because he believes it is not fair to others (i.e., he believes he would be taking services from others) and so he tends to tough it out. "I turn down a lot of stuff because I don't want to be the person (about whom) that's said, 'You got special treatment.'" He is convinced that his disability has turned his life upside down. "There's nothing positive about having arthritis. It doesn't make you stronger; it doesn't make you tougher. It beats you down." Along with several others (primarily those with LD), he struggles with the fact that he doesn't appear to be disabled and this complicates receipt of services (see an earlier quote under this theme). Anne (Lup) reported life changes as a result of her disability, including loss of her marriage and lack of sympathy from her children. She reported that Lupus is part of her now ("... yeah, like part of me") and that others are worse off. "I meet people worse than me, and I say, 'Wow, I'm still living.'" She noted that her priorities have changed significantly. Both Tia (LD) and Jean (LD/ADD) also reported that disability is part of them. Jean said that it is a part of who she is, and Tia, that it is a big part of her identity ("I understand who I am a lot more").

As with the last theme (II), there will be overlap with Theme V, as will become clearer subsequently.

Theme IV: Strategies and Supports.

Generally, all participants offered extensive information on formal and informal supports available to them, with the majority of their statements carrying a generally positive tone, although there were also numerous examples of support systems that were less than adequate.

Sue (blind) reported that agencies were generally helpful (e.g., CNIB), but some agencies don't give enough support and tend to stereotype you

("That was one [agency] that might have been a resource but wasn't... sometimes they will stereotype you in a group too"). She often devises her own coping strategies by trial and error; "I kind of make up my own strategies... I'm a trial and error type of person." Shakespeare (PPS) reported positive/supportive academics, very helpful university support services such as note takers, counselling support for frustration and depression, and strong support from family and husband. Her supports include creative/unconventional deliberate strategies, e.g., a scooter for mobility. She has found lack of support and understanding from some professionals, for example, doctors: "... the doctors would say, 'Oh no, it's just you must get used to it and it'll be all right.'" Her flexible program at the university helps her manage her learning.

Elizabeth (LD) found that employment services for individuals with disabilities were good. She learned coping techniques, e.g., taping lessons, color coding. Specific individuals stood out as offering particularly important support, e.g., a family friend referred her to disability services for diagnosis; as well as one professor ("He just took time to really talk to me about my interests and that sort of thing"), and one person at disability services, both of whom made her feel worthwhile and positive.

David (CP) gets disability support for attending university and, therefore, can't qualify for student loans, which adds to his financial hardship. Accessibility and mobility issues and the high cost of equipment are big concerns ("... it also affects me that my disability and the equipment that I need costs a great deal of money..."). He sees as impediments to his living with a disability that people with disabilities are seen as asexual, and the perception that people see the wheelchair as denoting mental disability, causing him to reject using a wheelchair. "When you are sitting in a wheelchair, you're not at eye level with people... it's almost like you're not on the same social level and people tend to associate wheelchair with mental disability." He believes that people with disabilities are looked down on and even scare others. He values a university education as his biggest goal to enable him to live a life with dignity. "That'll enable me to live my life in a way that's dignified... without having to worry about where the money is coming

from.” David has received strong support from his family regarding his right to equal treatment. He claims strong friendships with people who don’t treat him differently from non-disabled people. He received good support from a rehabilitation hospital (e.g., community enrichment program). Student services have also been helpful, but there is a lack of resources and housing. There have been supportive people at school and university, for example, services for the those with disabilities help with exams and contact professors when needed.

Smart (JRA) reports negative experiences regarding supports, such as poor assistive living supports (“Try living on eight hundred and fifty dollars a month”), unhelpful counsellors, and narrow career choices (e.g., teaching is possible because it is not physical). For him, it has been a very difficult process getting help and support as a disabled person: “As soon as you identify yourself as disabled to get a student loan..., you have to go see a career counsellor..., that’s one more thing that we have to do that’s draining and more painful and takes time, instead of making it easier...” He believes that inadequate support (“It was absolutely useless, the things they came up with”) is a waste of government money. Student support has been variable, some good, some not. There has been lots of “red tape” for obtaining services, such as grants, counsellor support and equipment: “No one had a clue who was responsible... The student-loan people said that I make too much money on AISH... I had to appeal five times... I didn’t get my student loan til the end of October...” The resultant stress from support limitations caused worsening symptoms (“... then the stress and the arthritis when through the roof”), and frustration with the red tape (“... and you get teary... but then you kind of suck it up and try again”).

Anne (Lup) has found that experts are less supportive than others who have Lupus.

Jean (LD/ADD) reported that a professor suggested testing for LD and this became a defining moment for her (“She continues to go out of her way to explain more things for me and just getting a different perspective... knowing about the difference has improved things...”). She has found lots of resources, university support staff have been very

good (“... they are very good at ...letting us... discover ... in our own way...”), providing, for example, extra exam time. She feels gratitude toward her helpers and wants to do well (“I’ve got to do everything I can because they’re making that time for me...”). She feels stress when things are not going well (“I think I even... referred to myself as a fake...”). She has been creatively devising her own innovative strategies and approaches, and her sister and friends have been helpful (“... my sister... being understanding and supportive... classmates... understanding and acceptance”).

Tia’s (LD) grade 8 teacher noticed something was wrong; however, the coping strategy used was wrong (e.g., “I’d just copy someone else’s work...”). Teachers and others have been significant helpers and supports; she has a sizeable support network (“I get a lot of help that other people don’t get and... lot of people could use that”). She was taught interventions such as time management, coping strategies, and understanding of LD (“They [student services] teach you how to understand your learning disability and how it affects your life”).

From the comments of the participants, it is evident that there is much valuable support available to post-secondary students with disabilities. However, it is also clear that there are gaps in service provision, particularly financial hurdles, that impede the positive student process and create additional burdens and stresses.

Theme V: Negative and Positive Changes with Disability/Transformational Outcomes.

All of the participants reported negative and positive changes as a result of disability, many of which can be classified as transformational outcomes from living with a disability, i.e., changes when a profound life event requires a major change (Aldwin, 1994).

Sue (blind) holds the belief that you must learn to be independent (“If you grow up always having to hold onto someone’s arm, always having to get help from somebody, you never have an opportunity to develop as an independent individual...”). She feels hostility to those with

disabilities who appear weak; "I've decided I don't want to be like them... I don't like to use the word 'weak,' but that's what I perceive..." She reported that the disability has changed her despite her resistance ("Well, I think it has as much as I've tried for it not to"). She commented that lots of things change, the way you think, the way people think of you and their attitudes. There is a dependence on others with loss of sight, and low expectations from others ("...other people telling you because they couldn't do it, then you wouldn't be able to do it."). These challenges have made her more resolute; "I think it's made me a stronger person... you do have fight through a lot of stuff..." Some of that "stuff" has been a loss of employment and difficulty finding employment. She has found that she must prove herself, prove her competencies, and disprove other's stereotypes ("... a lot of people have stereotypes or preconceived notions about what it would be like if you couldn't read...") She now has a different perception on life; "... and now... you're in that position, you just get the opportunity to realize that they're people that have disabilities... still real people..." Among new strengths, she reported a positive attitude, determination, becoming more easy going, and having good problem solving skills. In summary, Sue reported that, in spite of her resistance to change with disability, she finds that she has changed in many ways. Although she finds that she has to work hard to overcome others' biases and attitudes, must accept that she has some dependence on others, and feels hostility toward those with disabilities who appear "weak," the challenges have made her stronger. Transformational outcomes have for Sue been a different perspective on life and people with disabilities, and new strengths, including a positive attitude, determination to succeed and be independent, and new coping skills.

Shakespeare (PPS) had to re-learn computer skills and has surpassed her own expectations ("I lost all those kind of abilities and I've had to relearn them"). She has found determination to overcome problems and challenges, which has led to becoming more active; "I think with the challenge I've pushed myself to be more active." She had to give up many physical activities and she indicated that this took five years to accept. Negative changes have been loss of physical and other (e.g., computer) skills and abilities, but she has found strong determination to

overcome those challenges as well as acceptance of losses that cannot be overcome.

Elizabeth (LD) found it hard to accept the disability at the beginning; at that point she felt depressed ("The diagnosis of the learning disability was a catalyst to me to really take a nosedive..."). However, she stated that, ultimately, the diagnosis changed her life for the better. She has gained confidence in her own abilities and now understands her strengths and weaknesses. "I now understand my weaknesses and I am able to 'tackle' any situation from a perspective where I can utilize my strengths and minimize use of my weaknesses." Following the diagnosis, she has also worked to help others with disabilities. Elizabeth reported that she had to change her attitude to being positive about disabilities; this was a conscious decision to change herself and her life ("... [T]he most difficult thing... was actually changing my attitude... but I did"). She describes herself as independent, a survivor, and she had to learn to be forceful ("I had to learn to be more assertive... interact with people... which was difficult...and I have"). The disability makes her push harder to prove herself; "There's a part of me... that I feel that I've always got to prove myself... that I'm not stupid..." There is a resigned acceptance of her disability; she sustains this attitude with a sense of humor ("It's really not that bad... especially if you can attach humour"). The disability has caused her to learn about herself, recognizing qualities of persistence, resiliency, assertiveness, creative problem-solving, anger, joy, and relief. She is more articulate, and recognizes her strengths ("I've become more articulate... It's made me see what my strengths are..."). After initial negative experiences with the LD diagnosis (e.g., depression), she has come to a resigned acceptance of the disability, and made a conscious effort to maintain a positive attitude, a sense of humour, and recognize strengths and qualities including persistence and resiliency.

David (CP) now approaches things differently, with lots of patience and planning; "... you have to look at life in a completely different way and approach things with a lot of patience." The disability has, thus, changed his perspective on life. He has found that he needs to be positive, that a negative attitude isn't productive. "... [I]f I were to say,

'Why me,' and focus on everything that I cannot do in my life as opposed to what I can, I may as well pull up the covers and go to sleep for the rest of my life." He finds it rewarding to have people recognize his effort in living his life. He has become very organized, stubborn, and determined, with increased self-esteem; "... being very, very determined is really important." Earlier in his life, he avoided people with disabilities, "... until I got to the age of 21 and went to community enrichment... it really gave me a perspective on how far I have come and what I've tried in my life to make me who I am and see that I am a worthwhile person..." He feels bitterness that no amount of therapy can take away; "I just get so upset because there's no amount of exercising or physical therapy or anything that will take this away from me." He has had to learn to organize and advocate. He has become more spiritual, and believes "he is here for a reason." He has strong spiritual reflectiveness ("I definitely wouldn't be as reflective in a spiritual way if I wasn't disabled"), because it requires strength to maintain a positive attitude ("I've had to really build up my abilities to think in the positive and maintain a positive attitude"). As for other participants, David reported that, despite negative changes or consequences of disability, he has changed his perspective on life, working hard to maintain a positive attitude and build up his abilities. His spiritual reflections have been a strength in maintaining his strong positive perspective.

Smart (JRA) reports strong determination, describing education as his way of trying to get away from assisted living. He has taken strength from comments such as a professor's remark that "... you're a very remarkable person." He states, "I've just got to keep going... to suck it up and try again." He shows great persistence; "Appeal. I'm not dead yet; I wanted an appeal... I just can't give up... this perfect stranger (said), 'Keep fighting.' You shouldn't have to, though." He has no family supports, relies on personal tenacity, but feels he can't push too hard or use his friends too often. "There's no relying on anybody else... if something has to get done, I either do it myself or, hopefully, a friend is there for me. But then you have to be careful not to rely on friends too much." He has learned to protect himself; "...you've got to put up a wall... or you would go nuts dealing with what you're dealing with." About his disability, he says, "Live with it and do your best, but don't

pretend that it's made you a better person..." He rejects the belief that disability can be related to spiritual enlightenment. He has sat on boards and panels and become a self-advocate, and has learned strategies so he can deal with his disability. He stated, "I can't give up; what else am I going to do? I have to fight." Although Smart presents a very negative picture of the changes enforced by disability, there is great strength in his persistence, and his unwillingness to give up "the fight."

Anne (Lup) wants to start a Lupus group for women. She finds that she appreciates life more and takes less for granted ("I don't take things for granted the way I used to before..."). She states that she has greater appreciation for herself and others, as well as greater sympathy for others. She takes each day as it comes and appreciates it. She also appreciates her world and wants peace and harmony ("I've come to appreciate nature, environment... I just want peace and I wish (we) could live in harmony..."). Disability has changed the way she looks (e.g., loss of hair), and she has had to learn to appreciate herself, which has engendered self-assurance ("It has given me courage and confidence, and I've come out... I talk about it"). She has become more outgoing, has begun volunteering, has learned to accept death as part of life, and has become less materialistic. She now looks at life differently, and has different values. Disability has widened her thinking and she has become more spiritual; "I always feel there is a power above me and if I believe in that power I keep going. That's how much it has affected my way of living." Initially, she wondered, "Why me?" and has had to accept how it is. Now, she never gets annoyed, listens patiently, and works to create peace around her. "I listen now when people are talking... Now I take each one's word like there is a meaning out of it... that's how much I've come to appreciate others." She shows determination and tries to look strong. She is now more focused ("... the priorities are now different"), and wants to make others happy. However, she retains fear of losing her friends because of Lupus ("Should I tell them I'm sick...Will they understand or will they run away from me"). Anne expresses strong positive changes or transformations due to her illness and disability. However, there remain concerns, such as her concern about losing friends through disclosure of her condition.

Jean (LD/ADD) sees both positive and negative aspects of disability; she has become an advocate for herself and others, spending time consciousness-raising. She is learning to deal with her disability; "... it also kind of ... drives you." She tends to be sensitive and cautious regarding disabilities. She states that personal growth has been realized in creativity, intuitiveness, sensitivity, and empathy. She has elaborated on and created new and better strategies to share, some of which she has been urged to patent. Permission to do things differently, and getting to know professors better have been important strategies. She finds she is more curious, has more patience, empathy, a better sense of humor, is more detail oriented and self-reflective: "... [B]eing self-reflective and ... in tune... to what I'm thinking and how I'm doing things... it kind of helps me that I know what's going on." She is passionate about everything and everyone; "If you're passionate about something then it's going to serve you well." Knowing about LD and differences has also helped to shape how she lives; "I know knowing about the difference has improved things... learning certainly shapes a person as to... how they end up living." She is more stubborn, motivated by her disability, and determined that the disability is not going to stop her; "I think that can be a motivating factor... I'm not going to throw up my hands and give up." Overall, she finds more positive than negative aspects of disability ("I feel there's a lot more positive aspects to having a learning disability and ADD than there are negative..."). It seems clear that she has been positively transformed by living with a disability.

Tia (LD) finds that relationships are different (e.g., with family and others) as a result of her disability. People want to help, and to learn about LD; "... people really want to know and when I tell them, they... understand a lot better." She is learning that you have to teach yourself ("... [K]nowing that I had to teach myself, that was a big moment... it changed... the way you live your life"). Her spiritual beliefs, which pre-date her disability, give her strength. Tia reports changes in the way she perceives the world, in understanding her emotional states, and in feeling less anger. She has more confidence, is more assertive ("I have no problems putting my hand up [in class]"), and has lots of supportive relationships. She looks at life differently and understands things better;

“ I’ve been able to teach myself how to learn and how to... deal with life really... I think it’s made me a stronger person.” She has become more determined and never gives up (“I just have to keep trying and I think that really has made a big difference...”). In general, she takes a positive approach (“I could have looked at it as a... very negative thing... but I approached it as a positive thing”).

A consistent message from the participants is that, while disability may have some very negative aspects, a positive approach, such as the commitment to keep trying and never give up, has been a way of dealing with disability, resulting in personal qualities and dimensions that are personally, relationally, and perspectively transformative.

Conclusions

Before making any conclusions from the results or drawing any comparisons to parent life-management issues and transformational outcomes (e.g., Scorgie et al., 1996), it must be noted that only eight post-secondary students (only two males), with a limited range of disabilities and age of disability onset, were interviewed. Thus any comparisons and conclusions must be drawn with caution, requiring further research exploration for validation.

It is, however, clear that the participants in this study discussed (Theme 1) such issues as low self-esteem and negative feelings toward their diagnosis and assigned labels, as well as relief at finally obtaining a diagnosis. They faced issues such as fear of implications of disclosing their disability. Scorgie et al. (1996) reported parent concerns about seeking a diagnosis for their child, with consequences of relief as well as other concerns (e.g., disclosure) on obtaining a diagnosis and label for their child’s disability. For many participants, acceptance of the diagnosis involved a process that often began with negative self-perceptions (e.g., Elizabeth’s reference to her “dirty little secret”), to an acknowledgment that led to greater self-understanding (e.g., Tia’s comment, “Everything kind of made sense”). In addition, the degree to which the participants affirmed that disability interacted with all aspects of life (e.g., Jean’s statement, it’s “impacted on my entire life”) is

consistent with parents' comments that their personal and family lives often become organized around the special needs of their child.

Similarly, the challenges of disability (Theme 2), including fatigue, frustration, depression, loss of friends, limitations of choices, and financial issues, were reminiscent of parent concerns reported by Scorgie et al. (e.g., 1996). Several student participants, such as Shakespeare and Smart, experienced disenfranchisement and marginalization by friends and family members, similar to parents' experiences. In addition, some parents spoke of reduced vocational opportunities as a result of the caregiving needs of their children.

Identity issues and feelings toward disability (Theme 3) are less clearly matched with parent issues, not surprisingly because the parents' identities are not directly bound to their child's disability, though the parents are concerned about the effect of the diagnosis on the child's self-perception and valuing within the community. Diagnosis of disability did affect family identity and leisure interests.

Theme 4 (Strategies and Supports) comments are reminiscent of parents' comments and concerns (e.g., Scorgie et al., 1996). Some agencies, support services, and professionals are less helpful than others and support of family and friends is invaluable in managing life with disability. Student participants seemed to know their own strengths and weaknesses and attempted to tailor services to their specific needs. This underscores the need for individualized services for persons with disabilities and the families that support them. Families that located effective supports seemed to manage life more effectively. Alternatively, Smart's limited network of support resulted in feelings of aloneness and frustration, something also true of families.

Transformational outcomes for the participants in this study are particularly reminiscent of parent reports in our earlier research with parents of children with disabilities (e.g., Scorgie et al., 1996). The participants in this study reported personal changes, or transformations, as a result of dealing with disability -- changes in how they see themselves, as being stronger (e.g., qualities of determination,

persistence, confidence), more positive, having better coping skills. They reported changes in their relationships with others (relational transformations), such as in appreciating others and friendships more than before their disability, and becoming strong advocates for themselves and all individuals with disabilities. There were also reported changes in how they perceive their world (perspectival transformations), such as looking at life differently and holding different values. A number reported that they had become more spiritual in their outlook on life.

One interesting commonality in both studies was the degree to which participants recognized that their reaction to disability was a choice (e.g., Tia: "I could have looked at it as a very negative thing - but I approached it as a positive thing"). Like parents, the student participants avoided what they perceived to be negative responses (e.g., Sue: "I've decided I don't want to be like them") and focused on what they could continue to do over what was lost (e.g., David).

Finally, it must be stated, with caution, that there appear to be some similarities between themes reported by post-secondary students living with a disability, and parents of children with disabilities (e.g., Scorgie et al., 1996). One possible implication is that living with disability is transformative, whether directly to the one who is disabled, or to others closely associated with the individual with a disability. Clearly, further research is indicated to articulate the parameters of change and transformation, from living with disability.

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