LIVING AND LEARNING IN THE COMPANY OF CHRONIC HEALTH CONDITIONS:

INVESTIGATING PERSPECTIVES ON COPING AND RELATIONSHIPS

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Introduction

The prevalence of chronic health conditions (CHC’s) in the population is significant; 15-20% of all North American children live with chronic health conditions and/or disabilities (Berk, 2005). Children and families living with CHC’s face many stressors and challenges that can seriously impact both their learning experiences and their quality of life. For example, children with CHC’s experience disrupted school attendance, school avoidance, and academic difficulties more often than their well peers. They also encounter more physical difficulties, including: fatigue, poor concentration, changed body image; and more psychosocial issues, such as: frustration, social isolation, anxiety, depression, and poor self-esteem (Nevile & Roberts, 1999).

Counsellors and educators have both the need and the responsibility to be aware of these challenges and the “ways that work” for these children and their families, in order to provide appropriate, sensitive and responsive services.

This paper presents my research regarding the needs and issues of university students, and children and families who live with chronic health conditions (CHC’s). I will begin by describing my preliminary qualitative study: “Perspectives of Professionals” and its findings. This study investigated the viewpoints of three student service professionals regarding the needs, issues and strengths of university students living with CHC’s, based upon their experiences as a counsellor or advisor to these students. I will then link these findings to current theory including, a bioecological systems framework and a developmental, resilience–based orientation. Concepts including relational dialectics, to address conflict and interactive processes at the interpersonal and systems levels, and self-efficacy, to describe resilience processes at the intrapersonal level, shall be discussed. Following this, I provide a brief description of the larger mixed methods study I am currently undertaking, informed by these theories and looking from the other end of
the developmental and perspective spectrum: that of the child and family’s, during the ages and stages preceding university entrance. This second study will explore the lived experiences and patterns of coping and relationship that children and parents, living in the community with complex health needs (specifically, respiratory technology dependence), describe as “working for them.”

Context

Both of the studies I am presenting are situated in midwestern Canada. The first study was conducted at a mid-sized Canadian university, situated in a major urban centre, and serving a large, diverse region. The second study is being conducted in a major urban centre that also serves both rural and remote northern populations.

The social-historical context is of significance due to recent developments in both the healthcare and education fields. Advances in medical care and treatment have resulted in many more children surviving previously terminal and life-threatening medical conditions, who subsequently go on to live and learn in their home communities, often with accompanying ongoing medical needs (Rollins, Bolig & Mahan, 2005). Concurrently, the development and increasing influence of the disability rights movement in society has led to its structural integration, in 1982, with the Canadian Charter of Rights and Freedoms enshrining the rights of all citizens, regardless of ability, to equal treatment under the law (Dworet & Bennett, 2002). A related development is the recent paradigm shift in public education towards a more inclusive approach to students of differing abilities. This new direction is now becoming formally integrated into the structure of public education systems, with the passing of provincial legislation, and the introduction of inclusive practices and procedures within the school systems (Hutchinson, 2002). Furthermore, there has been a greater emphasis on early identification and
intervention with respect to learning difficulties, resulting in a greater focus on differentiated teaching within the classroom setting (Ibid). Children who have had the benefit of improved medical treatment and subsequently gone on to a successful learning experience at public school are graduating in increasing numbers. The effects of this development are now rippling out to post-secondary settings: universities are beginning to experience changes in their student populations. They have had to respond quickly, in order to begin to provide the equitable and accessible learning opportunities that are the hallmarks of inclusive practice and the formally acknowledged right of every student. Participants in the first study made particular note of the increases they have seen, with respect to students living and learning at university, in the company of CHC’s.

Perspectives of Professionals Study

This study was conducted to acquire an understanding of the counselling needs, issues and strengths of university students living with CHC’s (that could include a mobility disability), from the perspective of the student counselling and advising professionals on campus. Consideration was given to services contributing to student success and those requiring further development. Students identified as having a CHC were those requiring ongoing medical monitoring and treatment, ranging broadly from, for example: asthma, diabetes, muscular dystrophy, fibromyalgia, undiagnosed neurological disorders, to cystic fibrosis and cancer.

Method

Sample and Procedure

I recruited and interviewed three professionals employed at the university who had experience working with students living with CHC’s. Two participants were advisors in student disability services and one was a counsellor in student counselling services. I conducted semi-
structured one-hour interviews with each participant, in a private setting removed from their work area. To protect confidentiality, I have used pseudonyms to identify the participants, and other entities that arise in the data. To preserve the qualitative meaning of the study participants’ contexts, I have chosen to use an element of their departmental titles in referring to them, given the germane nature of their services in universities, generally.

Results

Data Analysis

Interview transcripts were analyzed for comparison purposes on a question-focused basis and, in a separate process, all data was coded according to themes and subthemes.

The Professionals’ Perspectives

Each of the participants presented their own distinct perspective and yet, side-by-side, their viewpoints fit together in consistent ways. Consideration is given to the professionals’ personal viewpoints regarding the students themselves, followed by a discussion of the themes that arose.

Findings

Perspectives regarding student characteristics

“Students first”. Participants’ descriptions of their personal response to students living with CHC’s included: admiration, compassion and respect for their commitment and desire to be a student, for example: “some of them are coming in with potentially life-threatening diseases, and are just saying, this is what I want to do with my life… they are just really… focused”. And the normalcy they seek: “first and foremost, they want to be like every other student” (Susan).

“Self-Advocacy: the fighters and the defeated”. Participants also characterized these students as being at either one end or the other, of the self-advocacy continuum, for example:
Some are very, very motivated, and very good at self-advocacy and they’ve kind of had to fight their way through everything up to this point… there are other students who, either haven’t fought or hadn’t known that they could fight, and so they come in very…almost defeated to begin with, (Jenn).

“Balance Managers”. Participants noted these students to frequently possess advanced time-management skills, flexibility and maturity as a result of their life with a CHC:
“they have to have learned to do more things more quickly for themselves that other people may not have had to… function better as a student.” (Paul).

Key Themes
A few key themes were repeatedly touched upon across the professionals’ perspectives. The variety of experience informing each participant’s viewpoint makes the presence of these shared themes all the more significant. The four main themes and respective subthemes to emerge are discussed below.

Theme I: Social Connections & Relationships

The importance of this theme cannot be overstated; it was touched upon the most frequently in all of the interviews, either as a topic of discussion (e.g. peer social connections) or as the main context of the professionals’ service provision. This theme is further delineated into the following two subthemes:

Subtheme I-A: “A Lifeline”: the student-professional relationship. Participants viewed this relationship as central to addressing the needs and issues of the students they served, featuring several key aspects:
1. Communication & advocacy, for example, with respect to the work of student disability services: “the main thing that we do, is for students to send out letters to their instructors so
they know what’s happening for the year,” and: “If there is no communication, it’s not going to work out.” (Susan).

2. The professional’s presence in relationship provides a vital form of support, for example:

…knowing that they can contact you by email or by phone, or having a drop-in time is really important, so that if they are feeling today is a day where they just can’t go on, and they don’t know where else to go… they can get in contact with me… students have said, it is kind of like that one lifeline that they’ve got, (Susan).

3. Providing services, including: interventions, problem-solving and making referrals when necessary: “sometimes they will come in crisis where they’re not sure what to do, they’re not sure what their options are… sometimes they need advocacy or referral to another resource,” (Jenn). And “There’s some cases where you have to ask the questions about well, can you really manage this much right now?... whether studying here right now is really in your best interest.” (Paul).

4. Maintaining clear boundaries and expectations, including the student’s responsibility for initiating contact, especially when they need help:

…we start off by saying these are the things I can do, and these are the things I can’t do… then because from that first appointment they don’t remember a lot, just saying, when you get in trouble, you have to remember to call me first… We don’t want to see them struggle through, and then lose it all, which sometimes we do, (Susan).

5. Student-centred orientation that is collaborative and normative:

Because first and foremost, they want to be like every other student, and then treating them like every other student is a great way to have that happen. So, be sensitive to their needs, but letting them guide that part of it, and where they want to go talking about it... (Susan).
Participants viewed this last aspect of the student-professional relationship as being in need of further development in the transition planning process at the high school level:

I think that is often forgotten…we have these meetings with the resource teacher, and the student’s not there, and I think the student’s the only one I am talking to when they get here, so I have to talk to them now…you have to let them play a part in their education plan, because they’ll tell you what they’re ready for. (Susan).

Subtheme I-B: Connecting with Peers. Participating professionals described the students’ ability to connect with peers as vital to establishing a foothold in the university’s student community, particularly for students living with chronic medical conditions, as they are more at risk of becoming isolated. The following description cogently sets out the meaning and significance of this subtheme:

I think connections are the biggest part…like any other students on campus, but more so because they’re already struggling with how their disability’s affecting their education, so if they made that connection in the first year that they are here, it will go that much more smoothly for them,… If you don’t have that, what reason do you have to keep coming back? You know, if no one is telling you this is the place for you to be…it’s really important. (Susan).

Participants noted that students’ social success at university seemed to be made easier if they had some previous experiences with success in social contexts - a valuable consideration in transition planning. In the case of students who lacked these connections, participants considered it important to offer referrals and encouragement:

…if you didn’t have friendships in high school because you were with an aide all the time and you didn’t have that opportunity to make those friendships, it is much harder at university, because you are so isolated, and we really try to encourage our students to get involved in student groups. (Susan).
Of particular importance, was understanding the students’ preference for mainstream activities:

…people want to be involved in what is out there already…going to a group with students with disabilities doesn’t really interest them, and I think that is because they’re like, “Yeah, I know this is what I have, like I want to go out and do some other stuff now,” (Susan).

Participants observed that some students seemed to have difficulties connecting socially at university: “sometimes there can be a lot of isolation and the feeling of not fitting in…” (Jenn). They viewed this, at times, as possibly arising from the student’s own lack of social engagement; Paul describes the awareness raising that he would use in discussing this concern with students:

…if they are feeling isolated, or if they are going into the depressive realm, (it) may be helpful for them to actually recognize that they need to engage themselves in being out and interacting with people and that may be something that they need to have built into their life as a student. (Paul).

Students’ health limitations were identified as potential obstacles to making connections:

…they might have more that they have to look after or attend to…it could be social activities…they may be able to or can’t manage physically or energy-wise…so they are under…real life primers that they have to function within that other individuals that don’t have those concerns have never really had to concern themselves with. (Paul).

A lack of community and feelings of stigma were also acknowledged as barriers:

…Especially on campus, when the students find lack of community, because they feel like they’re not normal, and at the same time, they don’t necessarily want to dive into a community that’s labeled “disability”…And so they end up in kind of a limbo,” (Jenn).

Participants described two ways that the social challenges faced by students with CDC’s could become reduced: First, at the systems level, they predicted that the recent development of inclusive environments in public schools will cultivate greater acceptance of variation generally, in the student population. Secondly, participants described the student’s own personal
comportment and self-advocacy, regarding their disability/health limitations, as being important to facilitating positive social connections and influencing the attitudes held by their peers:

…if you are meeting a person that doesn’t have a lot of experience with disability and your confidence and your comfort level with your disability and your ability to kind of set that out on the table and be real with it, if you can do that, and have that person go out of there feeling much more understanding of your disability and also disability in general, that’s a huge strength. (Jenn).

**Theme II: Awareness and Attitudes**

Awareness was a theme raised repeatedly by participating professionals as they described its contribution to student outcomes. They considered it to play an influential and interdependent role both systemically and with multiple players including: the student, the university, and the advisors and counsellors. Awareness in the context of this study refers to the possession of knowledge regarding the needs and limitations that may be present for students with CHC’s and the rights and services that they are entitled to.

**Subtheme II-1: Student Awareness.** Participants identified several key kinds of student awareness:

1. Availability of disability services: Participants noted that there has recently been a sharp increase in student awareness regarding the presence of services to support them at university: “Students just came out of the woodwork and said ‘I’m here and I didn’t know that you guys were here and what can you do?’ ” (Susan).

2. Right to services: Participants describe experiencing many students arriving on campus as empowered, expectant consumers: “now a lot more students are just saying ‘these are the services I expect and if your institution provides them, I’ll consider coming here and if they don’t, I’ll go somewhere else where they will’ ” (Susan). Their perspective was appreciative
of this new student awareness as informing a more assertive attitude: “students are taking control of who they are, and what they expect.” (Susan).

3. Degree of self-acceptance related to chronic medical condition/disability: Participants described students who possessed a matter-of-fact awareness and acceptance of their CHC as a part of themselves, as being in a far better position to manage their student life and build connections with others, than those who did not: “If you are not comfortable with your disability, then that makes it more difficult for other people to get comfortable with it.” (Jenn).

Jenn offers this illustration:

I am thinking of one student in specific…she’s very comfortable with her disability, and it’s a visible disability, and she’s very, she’s very outgoing, she’s very much self-advocating…I barely have to see her, because she does it herself, basically…she has her own little jokes about her disability and she has a very good sense of humour about that, and then there’s other students, where for them it’s not so much a joking thing, or they’re very self-conscious about it, and very lacking a lot of self-confidence, (Jenn).

This example illustrates the value of a self-possessed attitude and the student’s awareness and conscious efforts to set others at ease, related to differences in appearance and ability. It also affirms the very limited literature I have come across regarding constructive strategies for facilitating inclusive social interactions in educational settings (Frances, 2004).

Subtheme II-2: Awareness within the Educational Setting. Participants raised this subtheme consistently, with reference to the accessibility barriers that arise in the university context. Aside from simple inconveniences, participants maintained that a lack of universal accessibility awareness in building design, event planning and instruction delivery is detrimental to the student’s relationship with the setting and their academic life in general, for example:
…when planning doesn’t take into account for students who might have difficulties in certain situations, (for example, in one human services faculty) … the general orientation for all their new students…had stairs leading to it…so right there, the student is just entering the faculty, is already feeling like, ‘I don’t belong here, because they picked a place I can’t get into,… (Susan).

The participants perceived a need for greater awareness amongst academic staff, specifically to increase their understanding of students’ needs and abilities and to foster attitudes of acceptance and accommodation:

…in terms of their (faculty’s) knowledge of …I want to say “acceptance”, but “intolerance” isn’t the right word either…it should be more than that, just in terms of understanding that these individuals are people and they have needs like other people do, sometimes their needs are different, but they are every bit as much a student, every bit as much to have the potential to be successful…” (Paul).

Participants also extended this need for greater academic awareness and understanding to the secondary schools where, they noted, accommodations readily available at university were reported by students to be largely absent. This was viewed as evidence that much work still needs to be done in public schools to level the playing field for students living with CHC’s:

…I think things do get missed, especially when there are hidden disabilities involved…One example would be if somebody with a medical condition has difficulty writing because of pain or whatever, and they need exam accommodations, but they’ve…that’s never really been explored in high school, and so their marks suffer…so coming here and finding out you can have extra time, or use a computer, or whatever, sometimes that is a huge surprise…(Jenn).

Participants also held the view that secondary schools need to do more with these students to prepare them for the transition from high school to university:

I think it would be helpful to have the high school guidance counsellors…be able to bridge the gap between university and high school…for one, letting the students know that Student Disability
Services are available…if they were to say, ‘Disability Services, Counselling Services, Health Services, they are all available on campus, would you like to go for a tour?’…especially with the mobility stuff, ‘Would you like to have the SDS Advisor take you on a tour of the campus so that you can get comfortable with that?’ (Jenn).

**Subtheme II-3 Counsellor/Advisor Awareness.** Participants described several areas of professional awareness with respect to their practice and service to students with CHC’s:

1. Normal developmental issues: succinctly stated as follows,

   You know, just that wanting to be…fiercely independent, right, and then kind of going backwards into immaturity sometimes, and demanding certain things and then not following through…the majority of things that I see in my office are regular students’ issues, and the disability is just one piece of that.” (Susan).

2. Readiness for transition information at the secondary level: related to student development, “developmentally there’s…many students who are just…chronically thinking always about what and where they’re at, not what they need to know, or what they don’t know,” (Paul).

3. Boundaries and respect for the student’s right to self-determination in making decisions, including poor ones: “that was their choice, and they don’t want to talk about it, and they didn’t want to do anything …So, those pieces, you know, are very frustrating for me to watch, but I understand that they have to go through it,” (Susan).

4. Role of the family: “for us to be really aware of …how much their family has had to do this work for them before, and so not to belittle that in any way, because we still want them to…feel like they are a part of things, but that they can slowly let go.” (Susan).

5. Variation in personal perception of disability: “each student can have a different idea of what they want, or what…how they see their disability.” (Jenn) and the importance of providing an individualized approach: “what I like to do is get them to talk about what’s going on for them
and how their disability affects their schooling, so I can get a general feeling of what their attitude is.” (Jenn).

6. Social challenges & needs in living with a CHC: such as *dealing with stigma* at university, “it can be a very open place, but there is a lot of stigma there and lack of sensitivity” (Jenn).

Participants perceived that many students needed to learn additional skills to manage university and future career/employment demands, and they were developing programs to respond to these unique needs, for example, life coaching.

7. Professional’s responsibility to be informed about CHCs and related issues: participants acknowledged their responsibility to know about the students’ health conditions and their potential impact: “in cases where there are innate conditions that they are dealing with them physically or otherwise, it behooves people to *learn about those* in order to be of assistance,” (Paul).

Participants acknowledged that the student landscape is changing; new needs and issues are emerging as students arrive with medical conditions that professionals have not encountered before. It remains within their scope of responsibility to continue to learn and update their understanding of what these students must cope with in order to offer services that are relevant and sensitive.

*Theme III: Navigating the System*

This theme was raised consistently by participating professionals with respect to helping students obtain the services available to them. Participants identified several key aspects of this work, including: evaluating the extent of accommodations a student requires, often based upon the professionals’ judgment and experience: “… I often have new people coming in and they say,
‘is there some sort of manual that could tell me… what I can and can’t give to a certain student with this diagnosis?’…You can’t. You’re measuring it against experience.” (Susan).

From the participants’ perspective, the navigation process may begin with helping the student become more aware and accepting of their *own* needs (internal navigation), prior to becoming aware of the services that exist to support their efforts and the means by which to access them (external navigation):

…the bigger challenge is just navigating the systems within the University…Often navigating or assisting them in recruiting supports that they might need…they’re either unaware that they exist or that they may not be assertive about getting in place or needing some help getting those things in place. Or having them also accept that they might want or need some of those additional supports.” (Paul).

The necessity of navigating the system with respect to the student with mobility concerns was raised repeatedly by participants, in terms of the significant and pragmatic impact out-dated buildings have upon their daily life:

…if there are students who have decreased mobility, then definitely environment is a factor…in some buildings on campus in order to get to an accessible washroom, you have to go down three floors and over a building and up and all over the place…you have to schedule your classes so that you have time for a bathroom break in the middle. (Jenn).

Participants identified the key relational linchpin in system navigation as communication and collaboration between the student and the professional:

We can usually find accommodations that are going to put the students with the disabilities, whatever disability it might be, on more equal footing with any other student. My biggest challenge with that is when the students don’t come to me when they have problems, I mean we always encourage them to come and talk to us…but if they don’t come to tell us something, or if they assume that nothing’s available, then we can’t help them.” (Jenn).
Theme IV: Balance & Change

Participants identified the theme of balance and change as a contextual reality for students who live with CHC’s. Fluctuations in health status, treatment regiments, and the relentless and often unpredictable course of the health condition can play havoc with the student’s academic life, and for some, significantly alter their outcomes. The student’s ability to continually re-balance in response to changing capacities and needs was viewed by participants as essential to success:

I think that it cuts across all the panes of their life in terms of who they are as a student, a person, in life, work, and those are the things that they have to learn to juggle in addition to everything else that they have to do…they can be quite functional, or very high functioning…it is just very much dependent on the medical condition. (Paul).

Participants described the paradox students often encounter, when what they initially consider strengths, for example tenacity and motivation, later may become their downfall, if they are not flexible in responding to changes in health status: “it is a matter of pacing and knowing kind of what it is you can do and how much and how to manage that…for some of them… it is somewhat hard to predict that…’cause you can wax and wane or change…” (Paul).

A complicating factor participants identified was the dimension of time, which can impinge upon the future career hopes of students who are trying to balance their health needs with the temporal limits of their respective academic program: “one of the challenges is getting your program done, within “X” amount of time…if you have to withdraw from courses because of the illness, then that can be a real difficulty just getting through the program.” (Jenn). Participants described the difficult reality that, students need to maintain flexibility, in order to redirect their efforts should the education system’s doors close, due to time running out for their chosen program.
The student’s ability to balance their personal responsibility with their health related limitations, in terms of social and academic interactions was also viewed as important by participants:

I think sometimes people with disabilities go into kind of a “victim” mode where everything that happens to them is because they have a disability…but a bad grade is not necessarily because you have a disability, it could be because you forgot the date of the exam and didn’t study, right? A person being frustrated with you is not because they are prejudiced against you because of your disability, it could be because that person had a really bad day, or you were being very frustrating at that moment right?…we know that disability affects your job or your school work or your family, but…taking personal responsibility for the things that you do and how hard you try…There has to be a balance.” (Jenn).

Participants also commented on the need for balance in responsibility on the academic side, where well meaning, but poorly informed teaching staff, may unnecessarily lighten the responsibilities of students with CHC’s: “instructors will want to do so much that they’ll forget, like, okay, there’s some academic standards here, and we appreciate how nice you’re trying to be, but you also have to keep in mind with what those are, so it goes both ways.” (Susan).

Transition periods were identified as significant times of change in the balance of responsibilities: shifting from the parents to the student for example, with the step from public school/childhood into university/adulthood. While this shift can be very abrupt for unprepared students and their parents, participants found that students were able to emerge with their own resilience and confidence:

…if your child has had this disability with them for the majority of their life, and then you have been advocating for them all along, because you have to in the school system, when they get here, it is really hard for them not to push as much as they possibly can…but really great to see when the
student finally gets up and says, ‘I’m okay, I’m going to take this on my own now, and I can deal with it.’ (Susan).

Discussion

The perspectives of the participating professionals in this study shed light on the dynamic interdependent processes involved for university students with CHC’s and their campus based advisors and counsellors. Although these students were viewed as facing many challenges in university, participants noted that, like anyone else, they simply wish to connect with others in the learning and fellowship of student life. From the perspective of these professionals, the student’s transition to university and their adult life in general, is facilitated by self-awareness and acceptance of their circumstances, a supportive family and an inclusive secondary school that planfully assists with their transition to the university setting. Participants viewed secondary settings as able to facilitate the further success of these students through implementing inclusive education practices, providing supportive needs assessment and accommodation services, fostering student autonomy and positive self-awareness, and engaging students as collaborative partners in their transition planning process.

The participants’ perspectives also helped illuminate the facets of professional service that seem important to provide to students with CHC’s in university, particularly: being available to provide a supportive and facilitative relationship to them; helping them navigate their way through the university’s systems; helping them to acquire their social and academic footing and at times, keep their balance. Ideally, counsellors and advisors provide an accessible and collaborative relationship to students, including an ongoing supportive presence, informed by an understanding of their developmental strivings and health circumstances, as well as, providing other professional services as needed (e.g. advocacy, referral, crisis intervention, etc.). Together, through their collaborative efforts, counsellors, advisors and students can raise awareness and
sensitivity to CHC’s within the university, helping to transform the learning environment into a more inclusive, universally accessible place for all.

Limitations of this study include its small number of participants, single university campus, and singular perspective (professionals). Suggestions for future research to broaden understanding and provide greater context in this area include: gathering data from multiple sites, and obtaining perspectives from faculty, well students and students with CHC’s.

This is a small preliminary study, yet the data gathered offered some valuable evidence for specific theoretical approaches when considering the experiences of people living with CHC’s, particularly regarding interactions in the systems, interpersonal and personal dimensions.

Linking the Findings with Theory

Bioecological Systems

Context clearly plays a role in the experiences of students with CHC’s. Bronfenbrenner’s Bioecological Systems Theory offers the most differentiated and comprehensive framework for considering the contextual influences upon a person’s development (Birk, 2007). Using this approach, the student’s context is situated at the centre of the systems, within a small circle, known as the microsystem. The microsystem itself is nested within multiple concentric circles, representing progressively encompassing systems of social context, in which relationships are dynamic and bi-directional in nature. The student (in the microsystem) engages in direct interaction with the next layer, known as the Mesosystem (e.g., counsellor or advisor, professors, aids), has indirect interaction with the Exosystem (e.g., university administration, program planning staff) and is affected by the Macrosystem (e.g. societal values, attitudes, laws) and the Chronosystem (the passage of time) (Bronfenbrenner & Evans, 2000).
The relevance of this theoretical perspective was very apparent in the data gathered by the Perspectives of Professionals Study; frequent references to the various systems influencing the student’s experience at university were present in all of the interviews. For example, with respect to the Chronosystem, participants commented upon the significant increase in the number of students attending university with CHC’s over the past few years. Participants mentioned the related increases in rights to services, influenced by the Macrosystem: regarding more inclusive attitudes and laws. This has resulted in a response from the Exosystem: the university’s administration has implemented accommodation policies and provided student support services, including establishing and increasing staff within disability services. Advisors and counsellors, situated in the Mesosystem, provide direct services to the student (Microsystem) including facilitating relationships with other meso-level systems, such as the academic staff, student groups and various services. Participants also made reference to the pivotal role played by the students themselves, and their family (Microsystem), in making a successful transition to university. Many other examples of system related interactions can be noted in the findings presented. For example, accessibility issues confronting students with mobility limitations in aging buildings are the result of an exosystem factor: planning and building design, impacting the student’s (microsystem) ability to participate in learning.

Key to system interactions (described by Bronfenbrenner as proximal processes), are the people that these systems are composed of, leading to consideration of the interpersonal dimension.

Relational Dialectics

Baxter describes relationships as “complex dialogues” (2004), implying that relationships are made up of the reciprocal interactions occurring between the players which, while conveying
meaning, also form the very basis of the relationship and define the players (the one is defined by
the presence of “the other” engaged with them in interaction). The interplay between the players’
interactions is mutually dependent, while the dynamic tension sustained between them by their
distinct perspectives, like two poles, separates them somewhat, so that the relational process
moves along a spiral (or wave-like) path. This movement is dependent upon the ability of each
player to progressively negotiate the tension created by interacting with the other, which may
include points of conflict as well as acquiescence. This dynamic requires an interdependent and
continuous balancing process between the two players. If this balance is lost, for example, one or
both players become inflexible and therefore unable to deal with the give and take of interaction,
then blockage can occur, and the relationship can stall.

This theoretical perspective fits well with the data on the interpersonal, collaborative nature of
relationships described by participants in the aforementioned study. For example, participating
professionals described having to find a balance between service provision and the expressed
wants and needs of the students they served: determining when offered services were sufficient
(when a student could work something out for themselves) and when it was necessary to raise an
issue that the student needed to address. Examples of blockages included: students who blamed
the CHC for their study skill problems, and academic staff who doubted the students’ situation
for example, questioning their doctor’s note. In each case, the relationship’s progress was
disrupted by these positions, requiring resolution for progress to resume.

Important to understanding relational tensions and blockages is knowing about the coping
styles individuals tend to use in managing their experiences; some forms of coping are more
facilitative than others for building effective relationships.
Coping

Drawing upon the seminal work of Folkman et al (1986, p. 572), coping is viewed as the person’s cognitive and behavioural efforts to manage (reduce, minimize, master or tolerate) the internal and external demands of the person-environment interaction that is appraised as taxing or exceeding the person’s resources. Furthermore, coping has two major functions:

1. Dealing with the problem – referred to as problem-focused coping.
   
   Examples include: assertive and aggressive interpersonal interactions.

2. Regulating emotion – referred to as emotion-focused coping.

   Examples include: distancing, escape-avoidance, seeking social support, accepting responsibility, and positive reappraisal.

Folkman et al (Ibid) point out that people use both forms of coping in almost every type of stressful encounter, although their choices may be more or less adaptive.

Again, the study’s findings are consistent with this view of coping in students with CHC’s. For example, participants described students as situated at one end or the other of the advocacy continuum: “the fighters” when choosing assertive rather than aggressive strategies, provide an example of positive, problem-focused coping, while “the defeated” tend towards less constructive activities of learned helplessness, which could be considered a form of emotion-focused coping. However, “the defeated” students who seek an advisor or counsellor’s help to approach their difficulties, reveals a much more positive form of emotion-focused coping: seeking social support. This coping strategy, while also emotion-focused, has the potential to lead to a more satisfactory outcome and a change in the “defeated” student’s appraisal of the situation (not so overwhelming) and their ability to cope (this is manageable).
Significant to the coping process, is person’s appraisal of their capacity to manage a situation. People living with CHC’s, face the reality that not all problems can be resolved; chronic health conditions typically present adverse circumstances that must be lived with and adjusted to as they fluctuate over time. Therefore, while individuals may have well developed problem-focused coping due to the changing demands of their health condition, it is their emotion-focused coping that will become increasingly important for maintaining their sense of wellbeing. The individual’s intrapersonal appraisal of their capacity to manage their situation, is the lynchpin.

Self-Efficacy

Essential to effective problem- or emotion-focused coping is self-efficacy, a concept drawn from Bandura’s social cognitive theory (1997): Self-efficacy refers to the belief in one’s capabilities to organize and execute the courses of action required to produce desired attainments or objectives. Related to this is personal agency, which Bandura describes as the power to act in the world on behalf of yourself for your own established purposes – an essential ingredient for effective coping and stress management. Bandura is also mindful of the contextual nature of our existence, acknowledging the dynamic reciprocal nature of social interactions previously described in the systems and interpersonal dimensions: “We are all products and producers of social systems, personal and social change are complementary processes.” (Ibid, p. 7).

Participants in the aforementioned study described the students with CHC’s, who were managing university well, as possessing characteristics consistent with high self-efficacy and personal agency. Specifically, these students actively sought necessary resources and support, were aware of, and realistic about, their CHC and its impact upon their long term and day-to-day choices, and maintained a sense of humour and perspective about their situation. Furthermore,
these students tended to involve themselves in the social life of the university, interacting in a manner that informed and set others at ease with any perceived differences.

**Resilience**

The concept of resilience has recently emerged to describe such efficacious characteristics as those described above. This perspective is particularly salient for people living with CHC’s as it addresses the context that CHCs confront them with. Resilience, as defined by Rolland and Walsh, is: “the ability to withstand and rebound from disruptive life challenges. Becoming strengthened and more resourceful.” (2006, p. 527). This offers a proactive, person-centred stance, focusing on the inherent strengths and resources people use to address their adverse circumstances, thereby offering hope, in contrast to the pathologizing medical model.

**Conclusion**

The Next Study - The child and family living with complex health needs in the community:

Lived experiences and patterns of coping and relationship

Informed by the findings in the first study, I am adopting a bioecological systems framework and a resilience-based orientation for my second study. This study considers the experiences of children and families living with respiratory technology support to maintain their health, for example, tracheostomy and/or ventilatory support, part or fulltime (by mask or tracheostomy). These children often require multi-system involvement to live in the community, which can present real challenges for all concerned, but most particularly the child and family. Current literature indicates that there is a paucity in knowledge related to the patterns of relationship and coping that work for children and parents from their own perspective. This study seeks to address that gap. I will endeavor to do so using a mixed methods approach, collecting qualitative data (via semi-structured interviews) from parents and children living with these circumstances who
have been recruited from a pediatric respirology clinic in midwestern Canada. I will also gather quantitative data from parents, using a family information profile checklist I have developed and three self-report scales that align with the previously discussed theoretical perspectives. By using this approach I hope to obtain inter-corroborative data that is capable of reaching a broad audience.

Through this study I hope to address questions that have arisen for me during my years working with this population in my role as a child life specialist in hospital. Perhaps with a greater understanding of the perspectives held by these children and families, policy makers, service providers and the families themselves will gain a deeper awareness of what “works for them” and collaborate together to further develop the services and relationships that contribute to living well.

References


