Adolescent quality of life, Part I: conceptual and measurement model

Todd C. Edwards, Colleen E. Huebner, Frederick A. Connell and Donald L. Patrick

Few quality of life instruments exist that focus on the positive aspects of adolescence, incorporate adolescents' perspectives and language, and apply to both general and vulnerable populations. With these goals in mind, a conceptual and measurement model was developed using inductive qualitative methods to guide construction of the Youth Quality of Life Instrument-Research Version (YQOL-R). A conceptual model with four domains—Sense of Self, Social Relationships, Environment, and General Quality of Life—is reported.

Introduction

Quality of life (QoL) has received increasing attention in pediatrics and adolescent medicine in recent years (Bullinger and Ravens-Sieberer, 1995; Drotar, 1998). In part, this new emphasis reflects the growing trend toward defining health more broadly. Other influences include: advances in evidence-based medicine (Christakis *et al.*, 2000), an increasing cultural emphasis on the autonomy of youth that promotes self-evaluation (Levine, 1995), and the desire to compare the quality of life and its determinants among different population subgroups, particularly vulnerable populations such as children and youth with chronic conditions and disabilities (National Institute on Disability and Rehabilitation Research, 1998).

Improving health or QoL is the primary justification for many interventions with adolescents, such as medications, behavioural counseling, residential treatment, or different combinations of these and other therapies. Outcome assessments and evidence-based methodologies are needed to demonstrate the impact of different health conditions and the efficacy and effectiveness of interventions to health policy makers and consumers. A better understanding of the environment and subjective experiences of adolescents may also benefit adolescents and clinicians facing treatment decisions.

One major application of a QoL instrument is to assess the outcomes of interventions for adolescents with chronic conditions and disabilities, including common conditions that occur during development and disabilities or activity restrictions arising from impairments at birth or as secondary conditions (Patrick *et al.*, 1997). A focus on disabilities is important for improving the outcomes of interventions designed for the set of highly diverse conditions and disorders those adolescents present.

Among youth under age 18 years, disability rates increased from 1990 to 1994 (National Institute on Disability and Rehabilitation Research, 1998). There was a 33 per cent increase

Reprints requests and correspondence should be addressed to: Todd C. Edwards, Ph.D., YQOL, Department of Health Services, Box 358852, University of Washington, Seattle, WA 98195-7660, U.S.A. (E-mail: toddce@u.washington.edu). For information regarding use of the YQOL instruments go to http://www.yqol.org.

in activity limitations among girls, from 4.2 to 5.6 per cent, and a 40 per cent increase in activity limitations among boys, from 5.6 to 7.9 per cent. As a potentially underserved minority group, youth with disabilities would be expected to experience disadvantages in health and QoL compared with the general population. People with disabilities may experience lack of access to health services and medical care and may be considered at increased risk for various conditions (Healthy People, 2010). At the same time, however, it is important *not* to equate QoL with disability or functional status, and thus assume that adolescents with disabilities experience a lower QoL than those without (Patrick and Erickson, 1993; Patrick, 1997).

An extensive review of the adolescent QoL measurement literature conducted by the authors revealed a shortage of generic instruments that tapped perceptions or feelings. Not surprisingly, the majority of existing instruments focus primarily on functional status or the performance of daily activities considered important for children and adolescents (Starfield *et al.*, 1995; Landgraf *et al.*, 1996) or are disease-specific (Ingersoll and Marrero, 1991; Juniper *et al.*, 1996). Although these measures may be labelled "quality of life" or elicit perceptions, difficulties arise when comparing children and adolescents across functional abilities or conditions.

In this study we adopted the World Health Organization (WHO) general definition of QoL as people's "*perceptions of their position* in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns" [italics added] (WHOQoL Group, 1994; Bonomi *et al.*, 2000). QoL as defined this way is broader and more global than the concept of "subjective well-being" in reflecting the cultural and social context that defines *the good life* (Kahneman *et al.*, 1999, p. x). This definition requires that youth themselves define the important concepts and items, the measure employ subjective self-report whenever possible, and items be developmentally appropriate. For broad application with relevance to population subgroups, the measure should also be brief, be cross-culturally comparable and have a generic core applicable to all youth with specific modules for population subgroups containing non-overlapping content. Finally, quality of life also suggests a positive, "glass half-full" emphasis on health-enhancing aspects of life rather than a negative "glass half-empty" orientation of many assessments. For evaluating health and care disparities, the instrument should be appropriate for well youth and those who are sick or disadvantaged, and it should be used in conjunction with other measures that assess observed variables for comparisons of circumstances and perceptions (WHO, 1994). Moreover, it is hoped that the QoL paradigm with its positive assets approach will help identify sources of resilience and strategies of coping, which are rarely disclosed in deficit-oriented approaches.

This article reports on the development of a conceptual model for assessing generic QoL among youth 12–18-year old that is inclusive of those with physical and developmental disabilities who can report on their own lives. In developing the conceptual model, we conducted in-depth interviews with youth ages 12–18 with and without disabilities and from different settings based on residence (including living with parents or guardians and living on the streets) asking what was most important to their lives. Additionally, we consulted existing assessment instruments, such as the National Longitudinal Adolescent Health Survey (ADD Health) and conducted focus groups with adolescents, primary caregivers of adolescents, and child health and welfare professionals. A companion article reports on the initial validation of a new instrument that was derived from this model—the Youth Quality of Life Instrument—Research Version (YQOL-R) (Patrick *et al.*, 2002).

Methods

Data collection

Sources.   Two types of data were included in this study: (a) interviews with a broad range of adolescents ages 12–18 with and without disabilities; and (b) focus groups with adolescents ages 12–18 with and without disabilities, parents/guardians of adolescents with and without disabilities, and adolescent health and welfare professionals.

Participant recruitment.   Adolescent participants were recruited through flyers posted in Seattle-area community centres, churches, social service agencies, schools, hospitals, and through an ad placed in a youth-oriented weekly newspaper. Parent participants were recruited through newsletters, community centres, and a letter sent to patients homes by a regional health care provider. Child health and welfare professionals were recruited directly from the University of Washington Medical Center, teen health centres located on-site in Seattle-area junior and senior high public schools, and local social service agencies serving adolescents. The participant recruitment and data collection protocol was approved by the Institutional Review Board of the University of Washington.

Protocol.   Thirty-three in-depth semi-structured interviews were conducted with adolescents ages 12–18 years. The adolescents were approached to participate in the research project as "expert informants" to help design a questionnaire to assess adolescents' thoughts and feelings about their QoL. The interviews were one-to-one and were conducted by one of three members of the research team experienced in qualitative interviewing. Adolescents were recruited to be interviewed until the interview material became redundant and little new information was added.

The grounded theory approach.   The grounded theory method guided data collection and analysis (Glaser and Strauss, 1967). Grounded theory is derived from the sociological theory of symbolic interactionism (Blumer, 1969) and is used to model phenomena about which little is known. It is an inductive process approach, with an emphasis on social dynamics. The basic tenet of symbolic interactionism is that people construct meanings about their lives on the basis of interactions they have with other people. Thus, this approach is appropriate for describing QoL as defined above. It has been noted that qualitative modes of inquiry in paediatric research can provide ways of better understanding rare and understudied populations (including generating hypotheses and building theories), focus on the meaning or phenomenological experiences of patients and families, and shed light on the role of contextual factors in child health and well-being (Fiese and Bickham, 1998).

Our main goal was to elucidate and articulate as diverse a set of points of view regarding adolescent QoL as possible, *rather than obtain a representative community sample per se*. Strauss and Corbin (1990) described the logic of this approach as follows: "In terms of making generalizations to a larger population, we are not attempting to generalize as such but to specify. We specify the conditions under which our phenomena exist, the action/interaction that pertains to them, and the associated outcomes or consequences." (p. 191)

Sample.   A purposive sampling frame was devised which included the following categories: gender, age, ethnicity, socioeconomic status, sexual preference, disability/non-disability, in-school/drop out, and in-home/homeless. Eligibility criteria for all adolescents were: (a) 12–18 years of age, and (b) able to understand and communicate in English,

although it could be a second language. The following descriptive data were collected from adolescents in interview format using a brief sociodemographic form: date of birth, gender, ethnicity, with whom they lived most of the time, whether they were enrolled in school, grade in school, and parent's education level and occupation (if known).

The resulting sample was approximately evenly distributed among gender (15 males, 18 females), age (12–18), grade level (6–12th), and disability status categories (15 with disability; 9 mild-to-moderate cognitive, 5 physical, 1 combined). Most adolescents were currently enrolled in school, although four had dropped out of school after having completed no more than 10th grade. Two of these adolescents were currently homeless. Twenty-two adolescents were Caucasian, seven were African American, two were Hispanic, one was Asian, and one was Native American. Two female members of the sample self-identified as bisexual, and one male self-identified as homosexual. Most adolescents lived with one or both of their biological parents, and the majority were from middle and lower-middle class backgrounds. All adolescents resided in urban or suburban environments.

Interviewees were invited to discuss themselves, and others their age, in terms of their values, goals, personality characteristics, and place in their social network. Questions reflected developmental changes in self-concept and self-reflective thinking during the period of adolescence (Harter, 1990). Specific probes were used to illuminate stage-salient contexts of adolescence including home, school, work, and community (Bronfenbrenner, 1979) and to elicit an integrated view of overall QoL.

Interview.   The interview was pilot tested on three adolescents and modified to be more flexible and easier to comprehend. Specifically, questions were arranged to flow from the general to the specific. The first question simply asked whether the respondent had heard of the term quality of life and what it meant to him or her. If the interviewee said that s/he had not heard of the term, the interviewer defined it for him/her as follows: "We want to know how you judge if you have a good life or a bad life. What are all of the things you consider when you think about how things are going in your life?" The second question asked whether the respondent knew people who had a better/worse quality of life than him/herself, and if so, what made that person's quality of life better/worse. Finally, the respondent was asked about his/her health, and about a generic set of life themes (e.g. family, school, recreation, friends, etc.), as they related to QoL.

Focus groups.   In addition to the adolescent interviews, four focus groups were conducted composed as follows: (a) five adolescents without disabilities, (b) two parents of adolescents with disabilities, (c) four parents of adolescents without disabilities, and (d) seven adolescent health and welfare professionals. The data from the focus groups served as a validity check on the data from the individual adolescent interviews. In the adolescent focus group, participants were presented with a list of issues which came up in the adolescent one-on-one interviews, and were asked to elaborate on these and add any which they believed to be missing. In the focus groups with adults, participants were instructed to enumerate and discuss the range of issues which they believed important to the QoL of adolescents. One or more members of the research team moderated the focus groups. During the focus groups, the moderator wrote the issues generated on a large piece of paper visible to all participants. At the end of the focus group, participants were instructed to individually write on a piece of paper a list of the top 10 issues they believed affect the QoL of adolescents. Participants were free to include issues on this list which were not discussed in the focus group.

Participation in the interviews and focus groups was voluntary and participants were paid $15.

Data Analysis

The interviews were audiotaped and transcribed verbatim for use in analysis. A grounded theory (inductive) approach to data analysis was taken, whereby we did not start with preconceived notions or theoretical perspectives regarding the *substantive* nature of adolescent QoL. We took as our task to represent the range of these perceptions accurately, and to organize them into a coherent framework.

To help ensure that all relevant data were included in the analysis, at least two members of the research team (consisting of a sociologist, a pediatrician, a developmental psychologist, and a social psychologist) reviewed each interview transcript and highlighted text which seemed relevant to the interviewees' concept of QoL. The relevant unit of text could be a word, sentence fragment, complete sentence, paragraph, etc., depending on the form of expression given by the interviewee. The interviews ranged in length from 8 to 25 transcribed pages, and averaged 14 pages.

Coding strategies included *open coding*, assignment of codes to the text based on words or phrases that captured meaning in the data; *axial coding*, comparing open codes with each other to create relevant categories; and *selective coding*, using frequently occurring axial codes to create core categories, or model domains (Strauss and Corbin, 1990). All highlighted text was entered into a spreadsheet along with the interview and page number from which it came. The highlighted text was then printed and circulated among pairs of team members who individually open coded it for relevant contexts, experiences, or persons described by the adolescent.

The team members began open coding with a preliminary set of codes generated by an initial pass through the first several interviews by one of the investigators, and added new codes as necessary. Rather than require coders to reconcile their codes with one another, or to select only one code for a unit of text, all codes were retained for analysis. Thus, a particular unit of text could have more than one code assigned to it by one or more coders. In this way, the unique perspective of each team member was preserved, and particular units of text were allowed to represent more than one concept. Such flexibility at this stage of coding was designed to allow for the emergence and assignment of as many relevant codes as possible, and was balanced by a consensus process whereby each analysis decision in axial and selective coding had to be reviewed and approved by each of the team members. New codes were compared to existing codes and consolidated when appropriate. The team worked by consensus to sort the open codes into a comprehensive list of categories via axial coding, and then to sort the axial codes into a conceptual model of QoL via selective coding. Figure 1 illustrates the processes of open, axial, and selective coding.

In this example, the units of text which were open-coded were complete sentences or sentence fragments, as indicated in italics. Coder no. 1 coded the first sentence fragment as "persistence", while Coder no. 2 coded it as "self-efficacy". In addition, Coder no.2 coded the second sentence as "community support", and the last sentence fragment as "self-esteem". In the process of axial coding, 'self-efficacy' and 'self-esteem' were combined with other relevant codes to form the category, 'belief in self.' Likewise, later in the process of selective coding, the axial categories, 'belief in self' and 'being oneself' were combined with other associated categories to form the core category, "Sense of Self," which is one of the domains of the conceptual model discussed below.
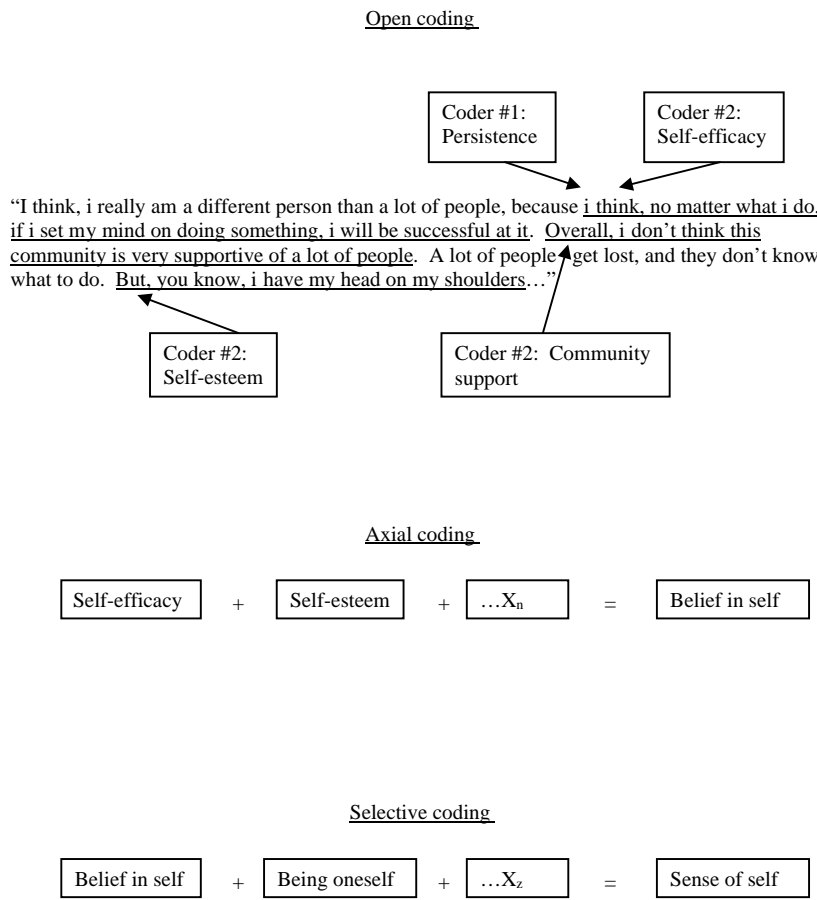
Open coding

Coder #1:
Persistence

Coder #2:
Self-efficacy

"I think, i really am a different person than a lot of people, because i think, no matter what i do, if i set my mind on doing something, i will be successful at it. Overall, i don't think this community is very supportive of a lot of people. A lot of people get lost, and they don't know what to do. But, you know, i have my head on my shoulders…"

Coder #2:
Self-esteem

Coder #2: Community support

Axial coding

| Self-efficacy | + | Self-esteem | + | …X_n | = | Belief in self |

Selective coding

| Belief in self | + | Being oneself | + | …X_z | = | Sense of self |

Figure 1. Example of open, axial, and selective coding.

Results

Adolescent interviews

When asked whether they had ever heard of the term 'quality of life", roughly half of the interviewees said that they had. Table 1 shows a breakdown of the themes which the interviewees spontaneously discussed (that is, prior to the use of probes) in describing their own QoL.

"Friends" the most frequently cited theme, with "family" running a very close second, and 'belief in self' and "school/learning" also being frequently cited. This is not to say that those themes which were less frequently mentioned at this point in the interview were not important to adolescents' concept of QoL, only that adolescents were less likely to discuss them spontaneously. The use of probes yielded a substantial amount of additional data, discussed below.

Table 1 *Themes which adolescents spontaneously cited as affecting their quality of life*

	n(33)		n(33)
Friends	20	Caring for others	5
Family	19	Adult support	4
Belief in self	17	Future	3
School/learning	14	Personal safety	3
Money/resources	11	Mental health	2
Participation	10	Freedom	2
Physical environment	8	Health	1
Engagement	7	Spirituality	1
Being oneself	6		

Adolescent focus group

No new themes were identified in the adolescent focus group which had not already arisen in the one-to-one interviews. This indicated that the individual interview data adequately represented the pertinent QoL issues among the adolescents in this study.

Parent and health professional focus groups

Although there was overlap between the themes adolescents discussed in the one-to-one interviews and those discussed by the adults in the focus groups, the adults tended to emphasize different themes. The following QoL themes were rated as important by every member in the respective groups: (a) health professionals: freedom from violence/safe environment (physical and emotional), belief in self, (b) parents of adolescents without disabilities: family, hope for the future, (c) parents of adolescents with disabilities: being accepted by peers, being with friends, not being seen as different, independence/self-reliance, attentive parents, self-esteem, and material things. Parents of adolescents with disabilities tended to emphasize the importance of friends and being accepted by peers more so than did parents of adolescents without disabilities or health professionals. In general, the adults rated being safe, hope for the future, and being accepted by peers more highly than did the adolescents.

QoL conceptual model

Through open and axial coding, a comprehensive list of codes was developed (Figure 2), and through selective coding a model with four main domains was established: (a) 'Sense of Self', (b) "Social Relationships," (c) "Environment," and (d) "General Quality of Life" (Figure 3).

The 'Sense of Self' domain pertains to the adolescent's feelings about him or herself. Several facets or subcategories comprise this domain: "belief in self", "being oneself", "mental health", "physical health", and "spirituality". "Belief in self" includes being willing to make mistakes and try or learn new things, persistence in the face of adversity, and efficacy in overcoming obstacles and achieving goals. "Being oneself" includes feeling good about yourself, being pleased with how you look, feeling comfortable with your sexual feelings and behaviours, and feeling important to others. "Mental health" includes feeling comfortable with the amount of stress in your life, not feeling alone, and positive/negative mood. For example:

> …You know, it's just kind of this whole new world of I guess adulthood that they don't really prepare you for…I think a lot of that's a responsibility on parents, and just like curriculum in schools, and I guess that kind of goes with society, that they don't bother to take time, they think you're gonna figure it out, you know? And I think that's kind of unfair… (interviewee no. 29)

Adult support
- Have role models
- Love, encouragement, support
- Respect, fair treatment
- Challenged, pushed to succeed

Be oneself
- "Place" to be comfortable, oneself
- Self-expression/communication (esp. feelings)

Belief in self
- Self-esteem, confidence, self-respect, pride in accomplishments
- Self-efficacy, overcome stress/obstacles
- Avoid negative peer influence, make good decisions/consider consequences, internal standards, positive attitude
- Acceptance of own shortcomings individualism

Caring for others, giving back, social concern
- Caring for others, make others happy/proud, look out for others, help others, sharing

Engagement
- Recreation/sports
- Entertainment
- Creativity
- Ecological concern

Family
- Caring, attentive parents
- Communication with parents
- Family life (incl. siblings)
- Relationship w/ parents & siblings
- Fair & consistent limits
- Challenged/pushed to succeed, expectations

Freedom to choose, act

Friends
- Confidant to share feelings, help out when needed, look out for each other, accept for who you are
- Belonging to a group

Comparison with others
- Be role model
- Sexuality

Future
- Opportunity
- Goals, dreams, a plan, visualization/persistence

Physical health
- Fitness/energy
- Ability to be active/independent/successful, do what you want
- Drugs are a waste of time & health

Mental health

Money
- Have nice "stuff" (i.e., car, clothes, etc.), money
- Have job
- Be wealthy/famous

Participation

Peers
- Treated fairly

Personal safety

Physical attractiveness

Physical environment

Quality of life (in general)
- Live fully
- Be happy/have fun

School, learning, education, curiosity

Spirituality
- Meaning/connection
- Guidance/morality
- Security, safety

Figure 2. Comprehensive list of open and axial codes.

"Physical health" includes having enough energy to do the things you want to do. Finally, "spirituality" includes having personal beliefs to draw on as a source of strength and feeling that your life has meaning.

The "Social Relationships" domain pertains to the adolescent's relations with others, and has the following facets: "adult support","caring for others," "family relations", "freedom", "friendships", "participation", and "peer relations". "Adult support" pertains to feeling that adults treat you fairly, and having conversations with adults about important matters in your
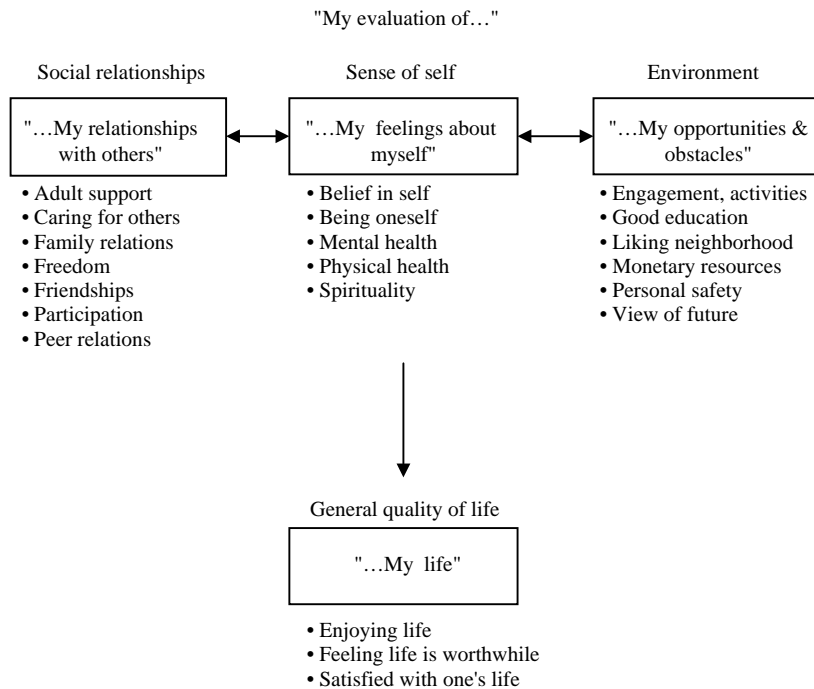
"My evaluation of…"

Social relationships	Sense of self	Environment
"…My relationships with others"	"…My feelings about myself"	"…My opportunities & obstacles"

• Adult support
• Caring for others
• Family relations
• Freedom
• Friendships
• Participation
• Peer relations

• Belief in self
• Being oneself
• Mental health
• Physical health
• Spirituality

• Engagement, activities
• Good education
• Liking neighborhood
• Monetary resources
• Personal safety
• View of future

General quality of life

"…My life"

• Enjoying life
• Feeling life is worthwhile
• Satisfied with one's life

Figure 3. Adolescent QoL conceptual model (selective codes).

life. "Caring for others" includes helping others, and being a role model for others. For example:

> …education is so important to me, also, because a lot of my friends don't really care about school. And it's sad, you know. I see a lot of them dropping out of high school…And I'd just like to be a good role model for them…I really want to be there, so, you know, 'I'm an example. If I can do it, you can do it. I'm here. I'll teach you how. I'll really guide you through it.[1] (interviewee no. 8)

"Family relations" includes getting the right amount of attention from your family, feeling understood by your parents or guardians, feeling useful and important to your family, receiving encouragement from your family, feeling that you are getting along with your family, and feeling that your family cares about you. "Freedom" includes feeling that your parents or guardians allow you to participate in important decisions which affect you, and feeling that you can take part in the same activities as others your age. "Friendships" includes being able to tell friends how you really feel, and being happy with the friends you have. For example:

> …You got to have friends, you know. You have to have a social life. You express your feelings. I know people that are 4.0 students, but can't communicate well with people. I don't think it's a good quality of life…I mean, that has to suck! I mean, you have no one to talk to, can't go hang out. (interviewee no. 10)

[1]Ellipses denote where text was excised by the authors.

"Participation" includes missing out on activities that you want to do because of physical or emotional problems:

> …And all my classmates in kindergarten they looked at me and didn't even want to come and touch me or be friends with me. I don't know if it was that they were afraid of me or they didn't like my disability… (interviewee no. 22)

Finally, "peer relations" includes feeling that you are treated with respect by your peers, and feeling unwelcome because of how you look.

The "Environment" domain pertains to opportunities and obstacles in the adolescent's broader social and cultural milieu. Facets include: "engagement and activities", "good education", "liking neighbourhood", "monetary resources", "personal safety", and "view of future". "Engagement and activities" includes feeling that your life is full of interesting things to do, and enjoying trying new things. "Good education" includes feeling that you are getting a good education, knowing how to get the information you need, and enjoying learning new things. "Liking neighbourhood" includes liking the neighbourhood in which you live. "Monetary resources" includes feeling that your family has enough money to live a decent life. "Personal safety" includes feeling safe at home and school. Finally, "view of future" includes looking forward to the future, and talking with others about your future:

> I'm scared that I am going to be on the streets like for I don't know how long. What if I can't turn my life around? You know [laughing], if I'm going to be like some person diving into a dumpster like you see. A lot of the kids up here get hooked on drugs and stuff I don't want to end up like that. (interviewee no. 20).

The "General Quality of Life" domain pertains to the adolescent's sense of how well his or her life is going overall. Facets include: enjoying life, feeling life is worthwhile, and being satisfied with one's life:

> …when I hear quality of life I just think of how people choose to live their life and if they are enjoying it and if they are doing the things they want to do…If they are having more good days than bad, [and] when they are having bad days they are supported by people, they are not by themselves. (interviewee no. 17)

Discussion

In this article we have examined the QoL construct as it relates to adolescents and have reported the results of a qualitative study in which we have developed a conceptual model to guide measurement. A companion article describes the validation of a new generic QoL instrument for adolescents, the YQOL-R, which was developed based on the results reported here. By asking adolescents themselves what is important to their QoL, we have attempted to keep the model youth-centred, based upon subjective self-report, and developmentally appropriate. By asking about both positive and negative aspects of QoL in the adolescent interviews, we have attempted to correct for the negative bias in many existing instruments. Finally, by including respondents from a diverse set of backgrounds and circumstances, we have attempted to encompass as comprehensive a description of QoL as practically possible, which applies to adolescents with and without disabilities. However, limitations on funding and funding scope did not permit acquisition of a fully diverse sample. No rural

youth and no youth in institutional settings were included. Another limitation is that the data collection method required ability to self-report, so adolescents without this ability were not included.

In terms of the conceptual model, we hypothesize that the effects of social relationships and environment are mediated by the outlook of the individual, i.e. how the individual *interprets* his or her context/situation (as per the WHO QoL definition). Of course, social relationships and environment have an effect upon individual outlook, but it may be the nature of the individual's outlook which is the key factor in determining QoL. A major implication of this view is that although an adolescent may live in a negative physical, social, and/or cultural context, he or she may yet experience a relatively good QoL depending upon his or her coping strategies and capacities in relation to that context. Alternately, an adolescent with ample socioeconomic resources and good psychological health might evaluate his or her position in life as relatively poor. However, these are empirical questions to be pursued in future investigations.

In conclusion, we found that it is possible for adolescents to articulate their views on the quality of their lives, from both a positive and negative perspective. The grounded theory method was useful for avoiding making assumptions about the determinants of adolescent QoL, and allowing the adolescents' own voices to be heard. The grounded theory method also facilitated clarity in conceptual formulation of the instrument described in the following paper.

Acknowledgements

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