

Adolescent Chronic Illness: A Qualitative Study of Psychosocial Adjustment

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Abstract

Introduction: The purpose of this study was to investigate the psychosocial issues facing young people living with a chronic medical condition. **Materials and Methods:** Subjects were young people with a range of medical conditions who were on a waiting list to participate in the Chronic Illness Peer Support programme at the Centre for Adolescent Health, Royal Children's Hospital, Melbourne, Australia. Young people agreed to in-depth interviews which were taped and transcribed. Thematic analysis was undertaken by two researchers working independently. **Results:** Thirty-five young people were interviewed. Thematic analysis revealed five broad themes: control (in control, under control, out of control); emotional reactions (happiness, frustration, anger, sadness, anxiety); acceptance (of illness, of others, of self); coping strategies, and; a search for meaning. The importance of social connections was emphasised. While illustrating the difficulties of managing a chronic medical condition during adolescence, a generally positive message emerges about these young people. **Conclusions:** Many young people with chronic illness appear relatively resilient in the face of the adjustment challenges presented by their illness. Interventions that allow a young person to explore meaning, build self-esteem, and acceptance through positive social connections are likely to improve adjustment outcomes in this group.

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Introduction

Chronic illness during adolescence can have significant psychological and social consequences within many life domains.¹⁻³ Growing up with a chronic medical condition presents many challenges including dealing with the symptoms of illness, side effects of medications, altered body image, unpredictable disease progression, depression and anxiety.⁴ Closely related are a range of social stressors such as restrictions on social and recreational activities and potentially compromised family and peer relations. Social stressors may be particularly important given that social health has long been thought to promote physical health through the "buffering" effects that social relationships have on stress.⁵⁻⁷

Despite the potential impact of illness during the period of adolescence, little is known about the kinds of psychosocial issues facing chronically ill young people in their daily lives. Adolescents with a chronic illness not only

face the usual physical, social and psychological changes of puberty, they also have to cope with the often unusual demands of illness management.⁸ Treatment demands and frequent hospitalisation can interfere with school attendance and the development and maintenance of peer relationships.⁹⁻¹¹ At a time of increasing independence, chronic illness may lead to greater dependence on the family, further increasing a sense of social isolation.^{12,13} It is not surprising that adolescents with chronic illness have been reported to be at elevated risk of emotional disturbance when compared to their healthy peers.¹⁴⁻¹⁶

Previous research has typically focussed on problematic aspects of adjustment to chronic illness (e.g., psychopathology, social dysfunction), often neglecting more positive outcomes emerging from growing up with chronic illness.¹⁷ Although chronic illness is a risk factor for poor mental health outcomes, young people with a chronic illness can move through adolescence to good futures and

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positive well-being.^{18,19} Healthy development, despite risks to the contrary, describes the resilient young person.²⁰ It is possible that a young person's capacity to find meaning in the experience of illness might play some part in their ability to tolerate the complexities of disease management and treatment.²¹ Indeed, understanding the psychosocial profile of resilient young people with a chronic illness may advance our understanding of more effective forms of intervention.

The purpose of this study was to systematically document the psychosocial issues faced by young people with a chronic illness using young people who had enrolled in the Chronic Illness Peer Support (ChIPS) programme. Since 1992, the Centre for Adolescent Health at the Royal Children's Hospital, Melbourne, has run a ChIPS programme for adolescents aged from 13 to 19 years.²² The initial programme runs for 8 weeks and involves weekly sessions in which young people have the opportunity to talk with other young people in similar life circumstances. Our clinical experience running these groups across the last 10 years suggests strong regularity in the kinds of issues that young people raise in each group. Seemingly, these young people have similar concerns about their peer, family, school, hospital and community experiences. The ChIPS programme is a rich source of information about the everyday lives of young people with a chronic illness.

Materials and Methods

Participants

Participants were young people on a waiting list to participate in the ChIPS programme at the Centre for Adolescent Health, Royal Children's Hospital, Melbourne.^{4,13,22} Young people attending the ChIPS programme live with a range of chronic medical conditions such as asthma, diabetes, and epilepsy. Referral to the ChIPS program is typically made by attending physicians, parents, or young people themselves. All young people who had signed up for the programme across a 12-month period were invited to participate in the study. Generally, the programme is for young people aged from 13 to 19 years. However, during this study we ran one group for young adults (20 to 24 years), all of whom agreed to participate in the study. Ethical approval was obtained from the Royal Children's Hospital Research in Human Ethics Committee.

Interviews with young people were undertaken prior to participation in the ChIPS programme with the aim of investigating the nature of psychosocial issues that young people with a chronic illness face on a daily basis. Interviews were semi-structured and covered four general domains as summarised in Table I.

TABLE I: FOUR DOMAINS OF THE SEMI-STRUCTURED INTERVIEW

Domain	Lead question(s)
Medical condition	Can you describe your illness for me?
Illness management	How well do you think you are managing your illness?
Lifestyle implications	What would your life be like if you didn't have an illness? How has your illness affected your life (enhanced or limited)?
Future aspirations	Do you have any goals for the future? How achievable are these?

TABLE II: LIST OF CHRONIC CONDITIONS

Condition	No. (n = 35)
Diabetes mellitus	5
Epilepsy	4
Asthma	3
Cystic fibrosis	3
Stroke	2
Chronic fatigue syndrome	2
Encephalitis	1
Acquired brain injury	1
Cerebral palsy	1
Systemic lupus erythematosus	1
Bladder extropathy	1
Crohn's disease	1
Familial dysautonomia	1
Achondroplasia	1
Lung condition (unspecified)	1
Heart condition (unspecified)	1
Bowel condition (unspecified)	1
Neuromuscular condition (unspecified)	1
Multiple conditions	4

To investigate the way young people build meaning around life and illness, a number of questions were also asked to explore the ways in which a chronic illness might impact on a young person's understanding of self, others, and the world. In particular, young people were asked to reflect on their sense of meaning and whether they had discerned meaning in their illness; sense of control over personal life events and the course of their illness; sense of worth to themselves, others, and the world at large, and; ability to accept that which is not amenable to change.

Analysis

Interviews were audio taped and transcribed. Interviews were analysed using a coding scheme that was developed on a sub-set of interviews. Transcripts were then thematically analysed by two researchers working independently. Themes were recorded where complete agreement between the two researchers was achieved. Disagreement was

addressed through discussion: if consensus was not reached, the theme was marked ambiguous and not recorded.

Results

All 35 eligible young people who had enrolled in the ChIPS programme over a 12-month period agreed to participate in the study. Participants were aged between 13 and 26 years (mean age, 16 years). Participants included young people with a range of conditions (Table II) of varying severity and stability. However, as this cohort was primarily recruited from a hospital-based service, most conditions were relatively severe.

Five broad themes were identified: control (in control, under control, out of control); emotions (frustration, anger, sadness, anxiety, happiness); acceptance (of illness, of others, of self); coping strategies and; meaning and reason. Each theme is discussed below with quotes used to illustrate the meaning of each issue for young people.

Control: In Control, Under Control, Maintaining Control

Unlike their healthy peers, young people with a chronic illness face the constant threat that their health might deteriorate or be exacerbated if management regimens are not maintained. Parents and health professionals alike emphasised the importance of keeping the illness under control through adherence to medical treatments and dietary regimens. The demands of illness management often place constraints around the young person. Not surprisingly, being in control had many meanings for young people participating in this study, commonly being represented as a struggle:

"I've always been a fighter. If I want to, I can minimise the effect of my illness or disability."
(16-year-old male)

Being in control was also seen as doing the "right thing":

"With my diabetes, if I have a healthy diet and do all the right things, I will feel better in myself and make myself better...I can help myself along the way."
(17-year-old female)

While maintaining a sense of control provided a sense of self-efficacy for some, it also required energy and commitment, which was recognised as sometimes being difficult to maintain:

"[My management is] probably medium right now. Not the best I could be, but not the lowest either. I get sick of doing all the things that I have to do—it also gets boring." (15-year-old male)

"Sometimes it [illness] can be good and sometimes it can be bad...It kind of depends on me."
(14-year-old male)

Successful management was often gained at the cost of other things in life. For example, many young people made comments about the impact of illness management on developing and maintaining friendships and an active social life:

"I'm managing well but I feel that I don't have any social life at all." (17-year-old female)

"Everything would be much simpler...you wouldn't have to go out and take your ventolin, and when you sleep over at people's places you wouldn't have to take your nebuliser." (15-year-old female)

Given the demands that many young people face in managing their illness, it is not surprising that young people can become tired and frustrated, fail to look after their health (e.g., through poor adherence to medications), and place themselves at risk for poor health outcomes.

Emotions: Frustration, Anxiety, Sadness and Happiness

Young people consistently made comments about the frustrations inherent in living with a chronic medical condition. Frustration and anger were terms that were commonly interchangeable:

"For about 2 to 3 months, whenever I had them [epileptic fits], I would get angry all the time. Frustrated." (16-year-old male)

"Scoliosis makes me feel a little bit angry. I am alright with my asthma." (14-year-old male)

Young people also talked about feelings of anxiety. However, it was recognised that becoming more familiar with illness symptoms and becoming better able to manage the illness could help reduce feelings of anxiety:

"It is different now because I am not as anxious because I am starting to get used to having it. If I have an asthma attack, I know what to do; I am not as anxious as I was." (15-year-old male)

Young people also experienced sadness in response to their situation. Their comments generally reflected negative perceptions of self and the future. Some concerns centred on never feeling normal or worthwhile. Others were focussed on feeling defective:

“I feel depressed at times...just about the condition. That causes other feelings like relationships...not having a girlfriend, which is probably because of my height.” (25-year-old male)

Although reporting feelings of depression, it is possible that such feelings reflect realistic disappointments that have arisen from a range of perceived losses associated with their illness rather than reflecting depressive schemas involving self-dislike *per se*. Thus, this sadness that young people reported may be usefully considered to be a kind of grieving.

Young people also reported a range of good experiences and positive emotional states. Feelings of confidence and happiness were described in a number of different ways. One young woman stated that:

“I feel confident that I can do what I want to do.”
(15-year-old female)

Another young girl said:

“I always set myself goals, and even if I don’t get anywhere with them, I still try.” (12-year-old female)

Among a range of negative emotions often arising from realistic sources, young people showed remarkable resilience, often overcoming the odds and forging positive emotional experiences and connections. In part, the capacity to experience positive well-being rested on the development of effective means of coping with adversity.

Coping Strategies

Young people reported using a range of coping strategies. Coping approaches involved behavioural strategies, such as the use of music:

“Music to me is probably the most therapeutic of all. It’s better than anything, [better than] alcohol, there is just something about it. It is like therapy for the soul.” (24-year-old male)

Other coping approaches involved cultivating a positive mental attitude to distressing circumstances or emotions:

“I would say that suffering happens and you can decide to make it a positive thing.”
(21-year-old female)

“I really think that if you do have something wrong with you, or something goes wrong in your life, you really do appreciate the good times more.”
(25-year-old female)

Less constructive coping strategies were also used, although they were recognised as being of limited value. As one young person said about his use of alcohol as a coping response:

“I haven’t found a constructive one at the moment. I find that everyone drinks at the weekend, so I drink but it’s only temporary.” (24-year-old male)

Another young person spoke of her self-harming approach to dealing with these negative emotions:

“I just feel like when I’m really bad I feel like hurting myself all the time, throwing myself against things.”
(16-year-old female)

Acceptance: Of Illness, Of Self, Of Others

Acceptance was seen as a central coping skill. Being able to acknowledge and accept their illness without making it a focus was an important goal for many young people:

“I think it might come down to accepting it, accepting that you have got it and dealing with it when it comes up and trying to work your way around it.”
(25-year-old female)

“I was asked what two things I would like to change. I said I would like to change the fact that I have this condition, and the second thing I would like to change is that I would like to accept it.” (21-year-old female)

An interesting relationship between illness acceptance and a sense of personal worth became apparent from many interviews: young people who believed in their own self-worth seemed to demonstrate a greater capacity to accept where they were at any one particular life point.

“Some people...don’t seem to have a high opinion of themselves and I am just one of those people that can accept my condition...and try to get on. I treat everyone the same and hope everyone sees me the same as other people.” (17-year-old male)

While this acceptance was much sought after in order “to move on”, it was clear that a young person’s capacity to accept their illness was a dynamic phenomenon. Working against their ability to accept their illness and the consequences was a strong desire to be normal:

“I know that I am not normal, like all the rest of my family are. I’m the only one with it. Even though I look normal, I am actually not.” (16-year-old male)

Acceptance by others was also highly valued by young people:

“People accept me and I feel like I relate to other people.” (16-year-old female)

“I feel loved and accepted...I accept them [people] no matter what condition they have, whether they have dark skin, light skin, or whatever, or illnesses.” (13-year-old female)

“I accept people more.” (15-year-old female)

A number of consequences were described as arising from lack of acceptance. Consequences included being teased, feeling socially isolated, having to respond to “annoying reactions” to their illness, and feeling the need to hide their condition. Teasing was a common problem, particularly for those in early adolescence.

*“I wish I did have no problems with my left hand, but it’s not going to happen. [The thing that really gets me] is being treated like s*** for something I can’t help.”* (16-year-old male)

Another young person spoke of the restrictions that were often imposed by others, saying:

“I tell my friends [about my illness]...but I don’t like to tell everybody because they might want to say ‘you can’t do this, you’d better do that, or I feel sorry for you’...I really hate it when people do that. It is really annoying.” (13-year-old female)

In addition to being teased, many young people reported physical and emotional isolation. They expressed difficulties making new friends because of both real and perceived restrictions from illness:

“I don’t like meeting new people because by the time they find out that I can’t do the things that they do they just don’t worry about me any more...they feel like they don’t know what to say and I really have only got one friend that I can talk to because he has the same thing as me.” (17-year-old female)

Meaning and Reason

Participants were asked about the meanings they might have about their illness. These questions elicited responses ranging from pragmatic (e.g., “it’s genetic”; “there are medical reasons”), to philosophic (e.g., “there is no reason, it just happens”; “there is an important reason”). As one young person said:

“I reckon there is a meaning behind everything and some things are extremely unfortunate.” (17-year-old male)

Others were prepared to create meaning from their particular situation and illness:

“I feel that now I am here, regardless of how I got here, I feel I can make myself have a purpose. I can create a purpose.” (21-year-old female)

This was not necessarily an enduring feature, however:

“Sometimes you feel like you don’t mean anything, but sometimes you feel really good about yourself.” (13-year-old female)

It was also true that some could find no meaning in their illness:

“There is absolutely no meaning to any of it. It’s a load of bull. It’s an unfortunate thing that happens with absolutely no meaning.” (14-year-old male)

“It’s like having your name drawn out of a cup sweep. Like last year I got the horse that came last, and I guess that’s what happened to me.” (14-year-old female)

Perceptions of illness being meaningless did not, however, indicate a sense of hopelessness or bleakness for the future, with many continuing to hold positive views about the future:

“I want to be a doctor...I might be a journalist or I don’t know, there are lots of things. I just have to choose. There are about ten different things I want to be.” (14-year-old female)

Many of these young people expressed realistic expectations of the future in that they talked of future plans that took into account what was realistically possible given their illness:

“I’d probably like to be an astronomer or an archaeologist. But you have to get really good [marks] with them and I don’t think that I would cope in the VCE year and all that. I don’t think I would get to school enough to do all that.” (16-year-old male)

Discussion

Living with a chronic illness in adolescence presents great challenges. This study suggests that while having a

chronic illness can make it difficult to feel normal, can compromise personal freedom and result in a sense of social isolation, young people generally meet these challenges proactively with confidence and energy. Consistent with this observation, young people spoke of frustration, anxiety, and sadness, but also spoke of much happiness in their lives. These different emotional responses were not simply described by different young people, but were described by the same person at different times.

Young people in this study reported a range of negative emotions (frustration, anger, anxiety) associated with their chronic condition representative of normal reactions to loss (or the threat of loss). While this study did not utilise diagnostic mental health interviews, there was little evidence of the more classical symptoms of psychiatric disorders that have been investigated in other studies of adolescents with a chronic illness.^{23,24}

Young people commonly talked about the frustration and anger they experience around the difficulty of building and maintaining good social connections with peers. Necessities of illness management (e.g., frequent hospitalisation, time-consuming or complex treatment regimens), aspects of parental behaviour (e.g., over-protectiveness), and aspects of peers themselves (e.g., teasing or bullying behaviour) were all cited as reasons why building and maintaining good social connections with peers was difficult. Young people conveyed a yearning for social connection and an eagerness to engage in life that made understandable their frustration and anger when these desires were thwarted by illness.

While compromised opportunities for social connection were often expressed as frustration and anger, threats to safety and self-esteem were often expressed in anxiety. Again, there can be little doubt that the experience of anxiety is often an appropriate emotional response given the range of unpleasant experiences young people with a chronic illness encounter in the course of treatment. Anxiety around safety was typically reported where a young person's sense of predictability and control was threatened. Many chronic conditions do behave somewhat unpredictably and young people legitimately experience loss of control. Little was reported in the form of unrealistic concern or unnecessary preoccupation with the vagaries of illness. In this sense, there was little evidence of the more classical presentations of anxiety disorders in this small sample of young people with severe physical disorders.

Unusual medical requirements, body deformities and skins conditions were commonly reported as sources of social stigmatisation and rejection, and were expressed as the cause of compromised self-esteem and social anxiety. These observations contrast with the findings of Wolman et al¹⁴ who suggested that invisible chronic conditions are

more commonly associated with poor emotional well being than visibly obvious conditions. Irrespective of the visibility of the condition, young people consistently identified positive self-acceptance as a critical attitude towards self that buffered the effects of negative judgements by others. For some young people in this study, an enviable form of self-awareness and acceptance replaced fear of social rejection. For others, such self-development was difficult and preoccupation with what others think more common.

Young people reported a range of coping approaches, some adaptive and some not so adaptive. While understandable, the problem of poor coping styles is when they lead to even less adaptive outcomes that then act to reinforce negative beliefs about the self and promote continued use of these same maladaptive coping strategies.²⁵ In contrast, positive coping approaches may serve to strengthen belief in the efficacy of self and assist in building core self-esteem. Young people spoke of the importance of developing coping skills, in particular developing self-valuing tendencies. Overall, young people in this study showed remarkable resilience, often gaining control over their illness management and persisting to minimise the impact of their illness on their daily lives. An interesting question is whether the peer support programme they subsequently engaged in can provide an effective context within which to build social connections, develop more adaptive coping styles and enhance self-esteem.

The life-enhancing aspects of adversity, such as chronic illness, have long been debated. An important component of resilience appears not to be the absence of difficult life experiences, but rather the ability to determine a positive perspective within the experiences.^{26,27} In this study, we asked young people about their sense of meaning, with the presumption that discerning meaning in experience is central to resilience.^{4,28} These young people had pondered personal mortality and the meaning of their lives with illness. Perhaps the most important dimension of a meaning system contributing to emotional resilience that they described was that of acceptance. Acceptance of self and a healthy detachment of self from the opinions of others seemed an important element of any system of meaning in which the young person had discerned a core of personal worth. Acceptance of illness and suffering seemed to emerge from experiences of the self as confident and able to handle life.

The observations of this study provide some important insights for intervention aimed at promoting positive adjustment in young people with a chronic illness. This study supports the importance of social support as a protective factor that can buffer the adverse potential of chronic illness during adolescence.^{29,30} Interventions that focus on fostering a sense of personal value through social

connections may assist young people to accept the reality of their illness and in doing so, facilitate their adjustment to life with a chronic illness. The use of peer support interventions provide young people with opportunities to experience themselves in new ways. Our previous research on peer programmes,²² such as ChIPS, suggests that spending time with other young people who are supportive and accepting because of the similarity of their life experiences can help build self-esteem and reduce young people's fear of being different and sense of social isolation.

The interview approach taken in this study allowed for in-depth exploration of psychosocial issues facing young people with a chronic illness that has added to our understanding of the impact of illness during the teen years. Not surprisingly, some of the questions did not seem relevant for some participants. In particular, the more philosophical questions about meaning and purpose, although answered readily, appeared to surprise some of the subjects. It is difficult to know what the novelty of this line of questioning may have done to influence young peoples' responses. Moreover, we do not know whether the use of a semi-structured questionnaire might be more or less valid in obtaining this information. Certainly, the themes brought up by young people in this study provide a robust basis for the development of a questionnaire capable of more systematic assessment of psychosocial issues in the lives of young people with a chronic illness.

An obvious limitation of the study is that because participants had enrolled for a peer support programme, they do not represent a random sample. Consequently, there are likely to be biases in selection that limit the generalisability of these findings. In particular, our experience of the ChIPS programme is that young people with more severe medical conditions are more likely to be referred, as are those who are perceived to be not dealing as well with their condition. Future research may also like to explore differences in psychosocial issues as a function of increasing age and maturity across the adolescent years.

Having a chronic illness in adolescence is not just about managing symptoms and preventing the development of more severe disease. While young people generally acknowledged the importance of these goals, they also acknowledged much broader goals in which physical, psychological, social and spiritual health were equally important. In the journey towards better health, young people talked about a range of social and emotional experiences, some positive and others negative, with little evidence of psychosocial disorder. Young people also talked about coping skills, some adaptive and some not so, and their evolving sense of meaning, at times difficult to forge and at other times stable and strong. The importance of attending to the whole person, rather than just treating

their disease, is immediately apparent from the findings of this study. To treat the disease without consideration of the broad range of psychosocial issues that confront the chronically ill young person is to compromise patient care. Any intervention that can promote psychosocial adjustment to chronic illness during adolescence is undoubtedly an essential component of effective adolescent health care.

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