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## Medical students' conceptualizations of quality of life associated with children who have Inflammatory Bowel Disease

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### Abstract

**OBJECTIVES**—To investigate second year medical students' understanding of quality of life associated with childhood inflammatory bowel disease (IBD).

**METHODS**—Cross-sectional study in a major teaching institution in San Francisco. A questionnaire was administered following an hour long gastroenterology lecture which featured two young patients with pediatric-onset IBD who addressed everyday life with the disease. Analyses of numerate responses to the questionnaire were paired with a content and thematic analysis of audiotape recordings of the patients' commentaries.

**RESULTS**—Medical student responses to the patient interviews were very positive. Medical students gained a new awareness of the psychosocial complexities associated with living with a pediatric chronic illness and a new way of thinking about the meaning of "healthy." Despite listening to two healthy young patients, however, the medical students still conceptualized pediatric IBD in mostly, although not exclusively, negative terms.

**CONCLUSIONS**—Medical students' perceptions of pediatric IBD improved as a result of listening to the patient interviews. While this teaching modality effectively introduced students to a complex condition, it did not overcome their unfavorable impression of IBD's impact on children's lives. The symptoms associated with IBD have stigma attached to them, and these stereotypes influence how medical students perceive those living with this chronic illness. More research and training in this area is necessary.

### Keywords

Chronic illness; pediatric IBD; quality of life; patient narratives; medical education

### INTRODUCTION

The prevalence of chronic conditions among children and adolescents in the US has increased since the 1980s<sup>1</sup> and is expected to continue to rise<sup>2</sup>. An estimated 5% – 31% of children under the age of 18 in the US have chronic conditions; this range reflects variation

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in data collection methods, definitions for childhood chronic illness, and measures for inclusion<sup>2-5</sup>. The increasing incidence of chronic disorders requires a change in focus when developing educational programs for medical students, who consequently need training in the prevention of disease complications and the maintenance of health for individuals with chronic conditions<sup>6</sup>. Research needs to address how distinct chronic conditions disrupt children's everyday life by altering developmental trajectories, daily routines, identity formation, family dynamics, and relationships with society.

Inflammatory bowel disease (IBD) is an unpredictable and potentially embarrassing chronic illness affecting over 1 million patients in the US. Characterized by periods of disease activity and remissions, it is commonly associated with symptoms such as intense abdominal pain, chronic diarrhea, nutrient deficiencies, weight loss, impaired growth and skeletal development, and delayed sexual maturation<sup>7</sup>. IBD ranks among the five most prevalent gastrointestinal diseases in the US, with annual health care costs exceeding \$1.7 billion<sup>7,8</sup>. Approximately 25% of patients are diagnosed during childhood<sup>8</sup>, and an estimated 100,000 children in the US have some form of it<sup>7</sup>. Few studies have focused on the quality of life of children living with IBD and their families, therefore relatively little is known about how children with serious chronic bowel disease manage everyday life.

The doctor-patient relationship is a key site of education for the patient and family unit. The unremitting nature of chronic conditions such as IBD, render this relationship increasingly important in the treatment and management of disease and the maintenance of health. Physician empathy is a fundamental component to developing an effective therapeutic relationship and is linked to positive health outcomes for patients<sup>9,10</sup>. Despite its importance in the doctor-patient relationship, empathy among medical students deteriorates as they progress through medical school<sup>11</sup>. Medical education and training contribute to this problem by encouraging depersonalization of interpersonal exchanges and objectification of the patient<sup>12</sup>. Efforts to address this loss of empathy have included calls to "humanize" medicine by embracing a more holistic view of the patient<sup>13</sup>, educational interventions designed to maintain empathy as students progress through medical school<sup>11</sup>, and examining informal and hidden curricula in medical education<sup>14</sup>. Furthermore, current medical training may not adequately address health promotion and disease prevention among patients with chronic disease, instead focusing on acute care over chronic care<sup>15,16</sup>.

The more physicians understand about both the pathophysiology and treatment of inflammatory bowel disease and psychosocial impacts on the (child) patient and his or her family, the better he or she is able to educate families and patients, be supportive and interact therapeutically. We hypothesize that the more exposure a medical student has to these issues during training, the better able he or she is to function effectively as a physician caring for a child or adolescent living with IBD. We tested this hypothesis by evaluating the immediate impact of a set of integrated learning experiences designed to introduce IBD to second year medical students during their participation in a series of lectures focusing on the pathophysiology of the disease process.

## MATERIALS AND METHODS

Medical students' perception of quality of life associated with IBD was assessed via a questionnaire conducted immediately following a gastroenterology lecture. This hour-long session featuring the illness narratives of two young patients with pediatric-onset IBD complemented several previous lectures addressing the patho-physiology and therapeutics of the disease. With some prompting and guided questions from the facilitator (a pediatric gastroenterologist - MBH), the patients presented their experiences with diagnosis, treatment, and impact of having this chronic illness on their daily lives including the way

they learned to live and cope with the unpredictable, embarrassing and potentially stigmatizing effects of IBD. The discussion was paused at different points to emphasize the broader significance of particular comments and their applicability and generalizability to children and adolescents with chronic illnesses. The facilitator highlighted and clarified important aspects of IBD illness experience mentioned by the patients and reinforced the idea that they were “normal people with chronic disease.”

The questionnaire (see online-only appendix, <http://links.lww.com/MPG/A231>) was designed and administered by a medical anthropologist (GS) trained in both qualitative and quantitative research traditions. This instrument was informed by in-depth ethnographic interviews with pediatric patients conducted by GS regarding quality of life among children with IBD. It was developed after consulting with health professionals involved in the care of pediatric IBD and medical anthropologists and peer tested for validity. To encourage medical students to participate, the questionnaire was brief, consisting of ten questions; half were closed ended and amenable to numeric analysis, while the rest were open ended. Demographic information was limited to gender and age. Participants were asked about their experience with IBD prior to the lecture, whether the lecture had influenced their awareness of the illness experience associated with childhood IBD, to consider how IBD affected children and adolescents psychologically and socially, and to comment about their perception of the quality of life associated with this disease.

Using textual analysis<sup>17</sup>, responses were coded, categorized and cross-tabulated by the socio-demographic and IBD experience of the respondents. Categories generated by the responses reflected positive, negative and neutral qualities as well as internal (rooted in the individual) and external (rooted in the disease) perceptions. Standard techniques for analysis of qualitative text data such as coding<sup>17,18</sup> were employed to categorize the emotional tone of descriptors provided in response to certain questions, and to identify themes occurring in the discursive responses to open-ended questions. Coding was performed by one investigator.

## Patients

The patients, a male pre-med college student aged 21 and female high school student aged 17, had well established doctor–patient relationships with the physician leading the gastroenterology lecture and had both participated in this lecture for three years previous. The young man was diagnosed with Crohn’s Disease at age 16 and the young woman with ulcerative colitis at age 9. The intent of lecture was to educate the medical students about the various domains affected by IBD via individual accounts from patients. The illness narratives chronicled the perspectives of children living with a difficult chronic illness and how it affected their daily lives. Complementing the lecture series, the patients addressed medical aspects of their experience with IBD, i.e. the symptoms leading to diagnosis, problems with being diagnosed, treatments and procedures, and side effects. Furthermore, they also addressed social aspects of their illness experiences, such as how having IBD has affected daily routines, school attendance, peer relationships, friendships, and family life - important psychosocial aspects that are not necessarily covered in medical school or apparent during medical interactions. The patients’ narratives of their personal experience with a sometimes physically debilitating chronic illness were punctuated by question-and-answer sessions.

The patients interviewed were very well adjusted; they had very supportive families who provided stable home environments, they had effective and vocal advocates in their educational settings, and access to medical care and medical providers committed to helping them manage their IBD. Nonetheless, their experiences reflect characteristics common to children and adolescents diagnosed with IBD.

### Sample: Medical Students

Typical for this institution, 85 of 141 (60%) of all eligible, second-year medical students (MS2) attended this gastroenterology lecture. Of those MS2 in attendance, 81 (95% of those at the lecture, representing 57% of the entire class) elected to participate in the survey. Slightly more women than men completed the survey. Differences existed within the sample due to socio-demographic characteristics or experience of IBD (Table 1). The vast majority had not encountered IBD before. Of those answering the specific question, 61 (80%) participants reported no personal experience with IBD prior to the lecture. Five (6%) reported experience with IBD in their family; 11 (14%) reported knowledge of IBD via acquaintances.

## RESULTS

Overwhelmingly, the MS2 responses to the patient interviews were exceedingly positive, with 98% of the respondents stating they learned new aspects of childhood IBD from exposure to pediatric perspectives of chronic illness, and 91% claiming the patient interviews prompted them to think differently about IBD. The Q&A generated questions focused on doctor-patient communication, the scope of disease impact on their lives, problems with treatment therapies, and coping strategies.

An open-ended question asked the MS2s to describe their perception of childhood experience with IBD following the patient interviews. This resulted in a preponderance of negative descriptors: of the 68 different terms generated, 41 (60%) were negative, 16 (24%) were positive and 11 (16%) were neutral. Table 2 lists all the descriptors and their frequency of use. Within the negative category, seven terms were used repeatedly: “Isolating”, “Pain”, “Difficult”, “Frustrating”, “Challenging”, “Scary” and “Embarrassing.” The remainder of the descriptors were cited notably fewer times, however, upon closer examination many were synonymous with each other and could be collapsed into larger groups, i.e. “Stigma”, “Misunderstood”, “Gossip”, and “Alienating” could all fall under the umbrella term “Isolating.” Collapsing these synonymous descriptors would raise the frequency of “Isolating” to 25.

As they most likely have more knowledge about the disease, its characteristics and trajectory, it was assumed participants with prior experience with IBD would have less negative perceptions of the disease than those without it. Sixteen participants, representing 20% of the study sample, reported previous experience with IBD either within their own family (6%) or acquaintances (14%). Despite greater familiarity with the remitting and recurrent nature of IBD and its psychosocial impact, this subset perceived quality of life associated with the disease in mostly negative terms (Table 3). Overall, this group accounts for 1/3 of all negative and 1/4 of all positive descriptors used to communicate the impression of quality of life associated with IBD.

### Perceptions of Childhood Experience with IBD

A series of recurring themes, underscoring an increased awareness of the patient illness experience and the humanization of disease for the MS2's, emerged from the discursive responses to the open-ended questions. Collectively, these themes reflect accurately the general impressions regarding IBD imparted to the MS2's, both in lecture and patient commentaries. These impressions include a new awareness of how the disease influences taken for granted aspects of everyday life, surprise at the patients' young age at the time of disease onset, the important role of adult advocacy in pediatric patients' lives, the effects of psychosocial factors on young patients' sense of self and their social relationships, and the existence of non-medical aspects associated with IBD that must be addressed. Individually,

the themes address participants' new awareness and perceptions of the different dimensions of the patients' illness experiences with IBD. Table 4 provides examples for each theme. Themes are presented in order of predominance.

**Puts a face on disease**—The dominant theme to emerge addressed the humanization of disease. The patient interviews humanized IBD for the MS2's and made it relevant in terms of their lived experience. Attending a lecture featuring patients discussing their personal experience with IBD allowed the MS2's to focus beyond the biology and pathology that define the disease to the individuals living with it and to the social and cultural factors that shape their reality. Several commented that a consequence of the patient interviews was that they identified with the patient and therefore were better able to relate to the disease. A notable finding was that younger students, those aged 21-30 years, identified to a greater extent with the IBD patients than did MS2's who were older than 30. Age more than gender influenced whether or not comments indicating "identification with" or "relating to" the patients were made.

**Children as social beings**—Refers to children's social engagement and interactions with peers and others. They are social beings who live, think, act and form relationships in the settings they frequent, such as school and home. Participants expressed an appreciation for the opportunity to reflect beyond the disease and the fact that it affects more than medical or physical arenas. The patient interviews underscored for them that children are "social beings" whose relationships with family, teachers, and peers influence their everyday life and that these relationships can have positive and negative effects on health management and outcomes.

**Forced Maturation**—This theme reflected the notion that children and adolescents diagnosed with IBD are forced to mature precociously. The MS2's repeatedly commented about the patients' advanced level of maturity and linked this precocious development with their illness experience. Study participants seemed impressed by the maturity level the speakers displayed, their active role in their health care and recovery and their composure educating a class of second year medical students about symptoms that might be considered embarrassing.

**Normality**—Several responses concerned the idea of "normality," a concept that is problematic due to its multiple referents and relativity. The theme collapses different comments concerning this notion to analyze taken for granted or invisible assumptions. The MS2's identified the patients as "normal" yet different, a contradiction that suggests they struggled with the label. The idea of "being healthy with a chronic illness" was new to some who found it useful and stated they planned to adopt it. However, some of the MS2 responses suggested at least some participants did not view the patients as "normal." Their responses are indicative of more familiar, pre-conceived, taken for granted notions associated with the definitions for "healthy" and "illness," notions that preclude – or at least put in a different context – the introduced in the lecture.

**Childhood ≠ disease**—The disjuncture of the patients being so young and yet dealing with chronic illness emerged as a theme. In the US, childhood is a time characterized by playing, learning, and growing; among the expectations of children is that they be healthy. Having a chronic illness is incongruent with this idealized expectation of childhood. Study participants displayed a general unawareness that IBD could afflict young children. Several expressed the idea that children belong to a category that is expected to be healthy and active.

## DISCUSSION

The purpose of this cross-sectional study was to assess whether medical students' perceptions of quality of life associated with IBD changed following this gastroenterology lecture featuring candid interviews with pediatric patients diagnosed with Crohn's Disease and ulcerative colitis. Our findings highlight the importance of humanizing disease to preserve empathy among medical students and signal the need for more awareness of contributors to perceptions of IBD.

### Humanizing disease

The majority of the study's MS2's (80%) reported no prior experience with IBD. Therefore, lectures addressing the pathophysiology and therapeutics associated with the disease were their introduction to it and its associated illness experience. The content of the patient interviews was valuable to the medical students as they showcased the patients as well-rounded individuals, not merely medical cases. Listening to patient narratives of personal, social and medical experiences complemented with their thoughts and feelings was instructive to the participants, many of whom already envisioned the utility of the newly acquired knowledge in their future clinical practice. The MS2's desire and ability to acquire narrative competence – “the ability to listen to the narratives of the patient, grasp and honor their meanings, and be moved to act on the patient's behalf” – will promote physician empathy and ultimately strengthen the doctor-patient relationship<sup>19</sup>. Furthermore, the responses of those MS2 participants in the younger groups suggest the closeness in age between the patients and themselves enabled them to better grasp the patient's perspective. Our survey suggests the MS2's enjoyed and appreciated learning from patients themselves about their personal illness experiences associated with IBD and that the lesson will not soon be forgotten.

The structure of medical education encourages medical students to focus almost exclusively on disease mechanisms, i.e. biology and pathology, to advance in their medical training. As noted, this decline in empathy as medical students progress through medical school is concerning as it is a crucial element of the doctor-patient relationship. MS2's are a crucial stage in their medical training as they prepare to enter clerkships where they interact with patients in clinical settings. Incorporating human variables, such as cultural beliefs, suffering, and agency in biomedical conceptualization of disease reinforces empathy, a key component of the doctor-patient relationship. As this study indicates, patient narratives are especially effective in introducing and linking human variables to biological understandings of disease.

### Perceptions of IBD

The findings demonstrate that the technique of using patients to recount their illness trajectories is a successful means of engaging and teaching medical students. This is particularly important given the sensitive nature of the psychosocial impacts of IBD. Interest in the quality of life among pediatric populations has grown in recent years leading to the tailoring of generic and disease specific instruments to better assess their experience with illness. In response to the lack of instruments for pediatric populations, the Impact II was designed specifically to measure quality of life in children with IBD<sup>20</sup>. Subsequent studies focusing on children and adolescents with IBD and their families found this population exhibits dysfunction and experienced more stress and less social support<sup>21,22</sup> and their quality of life is reduced in physical, psychological, and social domains<sup>23</sup>. Current research among children diagnosed with IBD indicate they can be hesitant to talk about their disease and symptoms, and in some instances they will limit their activities to have ready access to a bathroom<sup>24</sup>. A diagnosis of pediatric IBD is associated with risk for depression and reduced

psychosocial functioning<sup>25,26</sup>; it can adversely affect the lives of pediatric patients who must come to terms not only with its chronic nature but also with its associated symptoms which can be socially embarrassing, humiliating, and consequently lead to self-imposed isolation<sup>27</sup>. With regard to quality of life, individuals with IBD consistently scored lowest the questions dealing with emotional, social, and treatment domains<sup>28</sup>. To many participants in this study, the lecture was their first encounter with pediatric IBD, and despite listening to two healthy patients, actively engaged in the management of their disease, and with positive attitudes about their future, the MS2's envisioned the quality of life associated with IBD in mostly (albeit not exclusively) negative terms.

This finding raises questions about what contributed to this perception. Does knowledge about disease mechanisms inform expectations of quality of life for certain chronic conditions? Does knowledge about disease mechanisms override the patient's illness experience? Does the potential social stigma associated with the disease inform perceptions of quality of life? Does this perception inform doctor-patient interactions?

A key limitation to our study is that it is an account of a one-time/one-class assessment. We do not yet know how reproducible the results would be with other classes of medical students. Using different patients with, for examples, more or less positive life experiences, family support, or disease activity could also lead to different responses.

Advances in understanding of the etiology of IBD, its natural course, and drug therapies have proven effectual in treating active disease and inducing remission. Despite these medical developments, a diagnosis of childhood IBD increases the possibility of disruption of everyday life for the child and family, necessitates vigilance in taken for granted activities such as eating, and introduces uncertainty regarding health and the future. A logical next step is to investigate quality of life in children living with IBD and to identify the factors that contribute to it. Current literature addressing quality of life among individuals diagnosed with IBD overwhelmingly focus on adult populations. However, given that 25% of IBD patients are diagnosed with the disease during childhood, child-centered research investigating the quality of life associated with pediatric IBD patients is needed. The importance of such research is underscored by the consequences of childhood experiences as young patients develop into adults. Furthermore, combining quantitative and qualitative methods for data collection about conditions such as IBD will provide valuable information that is simply not amenable to one or other method alone.

This study thoroughly supports the need for a more sustained focus in medical schools and clinical teaching institutions on incorporating psychosocial aspects of illness into the curriculum. What happens in the clinic, especially during doctor-patient interactions, is immensely important for diagnosis, therapy, and management of symptoms and disease trajectory. It is important, however, to remember that the vast majority of a child's life takes place *outside* of health care settings. The larger context of a child's life has a huge impact on the child's ability to successfully deal with chronic diseases. This larger (social) context includes managing family and peer relationships, understanding and meeting societal expectations, navigating the educational environment, and developing their own personal interests. While a physician focus on therapeutic needs is reasonable, it is equally important that clinicians not lose sight of the larger context of pediatric patients' lives as children, too, are social beings. It is the task for preceptors and clinical faculty to teach medical students to more consistently pay attention to the larger context of patients' lives, and especially to discuss how chronic illness shapes children's lives and how, simultaneously, children's lives shape these patients' understandings of and responses to chronic illnesses, such as IBD. Lastly, the global burden of chronic conditions is increasing and requires a change of focus from treating acute disease to managing chronic ones<sup>29</sup>. Building strong doctor-patient



relationships to educate patients about their chronic conditions, empower them to manage their health, and improve quality of life are more important than ever.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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**Table 1**

## Medical Student Demographics

	Males (N=36)	Females (N=45)
<u>Age Ranges (years)</u>		
21-25	20 (56%)	26 (58%)
26-30	12 (33%)	16 (36%)
31-35	3 (8%)	3 (7%)
36-40	1 (3%)	0
<u>Previous experience with IBD</u>		
None	29 (83%)	32 (76%)
Family	3 (9%)	2 (5%)
Acquaintance	3 (9%)	8 (19%)

**Table 2**

## Perception of Childhood Experience with IBD

Negative	126	Positive	22	Neutral	12
Isolating	21	Strengthening	3	Need Strong Support Structure	2
Pain	19				
Difficult	13	Manageable	2	Need Compassion	1
Frustrating	12	Surmountable	2	Advocacy	1
Challenging	12	Maturing	2	Management	1
Scary	11	Responsibility	2	Attention	1
Embarrassing	9	Normal	2	Understanding by others	1
				Socializing with others	1
Stressful, Frightening,	5	Introspection	1	Humbling	1
Confusing		Confidence	1	Self-Image	1
		Positive	1	Coping with complications &	
Fear	2	Personal Growth Experience	1	symptoms	1
Fatigue	2	Inspiring	1	Not life threatening	1
Tiring	2	Courageous	1		
Uncertainty	2	Hopeful	1		
Inconvenient	2	Beatable	1		
Different	2	Survivable	1		
Overwhelming	2				
Time consuming	1				
Unfair	1				
Arduous	1				
Peer Pressure	1				
Incessant	1				
Draining	1				
Misunderstood	1				
Devastating	1				
Traumatic	1				
Demoralizing	1				
Tired	1				
Taxing	1				
Daunting	1				
Gossip	1				
Why me?	1				
Worrying	1				
Stigma	1				
Burdensome	1				
Annoying	1				
Alienating	1				
Nuisance	1				

<b>Negative</b>	<b>126</b>	<b>Positive</b>	<b>22</b>	<b>Neutral</b>	<b>12</b>
Odd	1				
Change in Lifestyle	1				

**Table 3**

## Term Frequencies

Negative	38	Positive	5	Neutral
Isolating	7	Personal Growth		
Painful	6	Experience	1	
Difficult	5	Strengthening	1	
Challenging	4	Maturing	1	
Frustrating	3	Responsibility	1	
Scary	3	Surmountable	1	
Embarrassing	2			
Different	2			
Uncertainty	1			
Stigma	1			
Multiple Bathroom				
Trips	1			
Demoralizing	1			
Confusing	1			
Self-image	1			

**Table 4**

Themes and Examples. Not all examples included.

Themes	Examples
Puts a face on disease	<ul style="list-style-type: none"> <li>• Put a face on disease. I will definitely remember it more. Also, I have a better understanding of the difficulties patients go through.</li> <li>• They reminded me how the list of symptoms on paper can have profound effects on the real functioning of actual people.</li> <li>• Gave a human face and experience to a disease. Helped me to relate to disease more.</li> <li>• I'd previously thought of these diseases as affecting older people who, at least in some way, were less like me.</li> <li>• I have never been exposed to people my age having IBD.</li> <li>• Understanding the effects of treatment on returning to school was especially interesting.</li> <li>• It gives a more complete clinical picture particularly with regards to daily life and long-term issues.</li> <li>• I think it helped to make students more sympathetic to the symptoms we read about in black and white.</li> </ul>
Children as social beings	<ul style="list-style-type: none"> <li>• [Patient interviews changed awareness of] more personal aspects of the condition than just the medical parts.</li> <li>• Made me aware of the non-medical aspects of care that need to be addressed.</li> <li>• It made me think more about the difficulties facing children with disease at school, peer acceptability, etc.</li> <li>• There were obvious social pressure from school and peers, which caused anguish in the patients.</li> <li>• Feel distanced from peers and misunderstood, which can either promote greater independence and self-confidence or ostracization.</li> <li>• I would imagine it would cause them to withdraw socially and would predispose them to psychological issues such as depression.</li> <li>• Challenging because the children are having a different experience than their peers.</li> </ul>
Forced maturation	<ul style="list-style-type: none"> <li>• I think it makes them mature a little faster than most.</li> <li>• [IBD] causes them to think more responsibly about their bodies.</li> <li>• These two patients are both incredibly mature and articulate. It seems that their experiences have really made them grow up more quickly.</li> <li>• IBD forces adolescents to assume an active role in their health maintenance which requires a level of maturity well beyond their years.</li> <li>• They are pushed to develop very mature social and communication skills.</li> </ul>
Normality	<ul style="list-style-type: none"> <li>• It can make someone feel abnormal or stigmatized, especially when it occurs at an age when people are expected to be healthy and people are marked for being unusual.</li> <li>• I think my perception of people with IBD changed from "sick people" to "normal people with a challenging disease."</li> <li>• Takes time away from being a normal child.</li> <li>• People with IBD are normal people with disease and are only trying to love normally despite their illness.</li> <li>• Limited activities that one would normally participate in.</li> <li>• Kids want to be normal. I think about adult life after...it must affect their image of themselves and what they see as possible for themselves as adults.</li> <li>• The "normal, healthy person with chronic disease" concept was new to me.</li> </ul>
Childhood disease	<ul style="list-style-type: none"> <li>• I did not think the age of onset could be so young.</li> <li>• It can make someone feel abnormal or stigmatized, especially when it occurs at an age when people are expected to be healthy and people are marked for being unusual.</li> </ul>