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Child and Parent Perceptions of Monitoring in Chronic Illness Management: A Qualitative Study

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Abstract

Background—The management of a childhood chronic illness can be challenging because it can involve frequent and complex treatment tasks that must be carried out on a daily basis. Parental monitoring of the treatment regimen and child disclosure of health-related information may impact effective illness management but are not well understood.

Methods—The present study utilized qualitative methods to examine parental monitoring-related behaviors, youth disclosure of health-related information, and both perceptions about, and reactions to, these behaviors in a sample of youth diagnosed with a chronic illness (e.g. asthma, diabetes and cystic fibrosis) and parents of youth with one of these illnesses.

Results—Parents solicited information from youth verbally, observed symptoms, reminded youth about treatments, and tracked indicators of treatment adherence (e.g., dose counters; glucose meters). Youth reactions varied from acceptance to irritation. Youth behaviors included withholding information and freely disclosing spontaneously and in response to requests.

Conclusions—Findings derived from this qualitative methodology demonstrate convergence with findings from quantitative studies on this topic, add to the literature related to parental monitoring of chronic illness management, and suggest several avenues for future research.

Keywords

health; parent perceptions; chronic illness

Parental monitoring traditionally refers to a set of parenting behaviors relating to parental oversight of the child's activities. Within the past decade, it has come to light that most prior studies of parental monitoring assessed what parents know, not what they actually do (Kerr and Stattin, 2000; Stattin & Kerr, 2000). By focusing only on what parents know, these measures ignored the processes that beget parental knowledge, including child disclosure of information (Kerr & Stattin, 2000; Stattin & Kerr, 2000). Consequently, the construct of parental monitoring is being revisited with more depth, complexity and methodological specificity across disciplines (Barber, Stolz & Olsen, 2005; Fletcher, Steinberg, & Williams-Wheeler, 2004; Soenens, Vansteenkiste, Luyckx & Goossens, 2006; Crouter & Head, 2002).

Parental Monitoring of Chronic Illness Management

Childhood chronic illnesses (e.g., type 1 diabetes) present a unique challenge to parents, who must oversee a complex treatment regimen and balance treatment tasks with other child and family responsibilities and activities. Effective monitoring of the treatment regimen is of critical importance, because regimen adherence has been identified as a key predictor of positive health outcomes (Drotar, 2000; Quittner, Modi, Lemanek, Ievers-Landis & Rapoff, 2008). However, the monitoring process can be difficult, because youth may view parental monitoring behaviors as unnecessarily limiting independence, especially during adolescence.

Quantitative studies of parental monitoring with this population have encountered methodological problems similar to the problems that had occurred in studies of healthy children and youth; in lieu of measuring parental knowledge and monitoring processes separately, these constructs tended to be lumped together under the umbrella “parental monitoring” term. Fortunately, this issue is being acknowledged and rectified through re-examination of existing data such as in the case of the Parental Monitoring of Diabetes Care Scale (PMDC) (Ellis et al., 2008). Parental monitoring was originally conceptualized as a unitary construct consisting of supervision of diabetes care tasks, awareness of episodes of nonadherence, and parental presence during task completion. In a re-evaluation of the data, Ellis and colleagues (2008) analyzed the items on the PMDC in such a way that was consistent with more recent conceptualizations of parental monitoring. This change resulted in the new finding that parental knowledge mediated the relationship between parental monitoring behaviors and treatment adherence.

Additional quantitative research has supported positive associations among parental monitoring behaviors and youth health outcomes. Among adolescents with type 1 diabetes, regimen adherence was found to be positively associated with parent-adolescent relationship quality and parental monitoring (operationalized as perceived knowledge of diabetes care activities) (Berg et al., 2008). In this study, parental monitoring partially mediated the effect of parent-adolescent relationship quality on adherence and was also associated with metabolic control of diabetes. Another study with youth diagnosed with diabetes found that parents who were perceived by children as critical and coercive (i.e. less warmth, trust and support) with respect to their attempts to manage the child’s diabetes, had children who were more likely to demonstrate weak regimen adherence (Duke et al., 2008). Further, maternal presence during medical tasks has been shown to be related to greater adherence to the specified frequency and duration of nebulized treatments in a study of preadolescents and adolescents with cystic fibrosis (Modi, Marciel, Slater, Drotar, & Quittner, 2008).

While some research has been conducted, monitoring in families with children with a chronic illness is not well understood and has largely been assessed quantitatively using disease-specific instruments (Berg et al., 2008; Duke et al., 2008; Ellis, Templin, Naar-King, & Frey, 2008). Using qualitative methods, Leonard, Garwick and Adwan (2005) found that adolescents diagnosed with type 1 diabetes with good metabolic control perceived their parents’ monitoring behaviors more positively than adolescents with poorer metabolic control. Similarly, in families with a child diagnosed with type 1 diabetes, parents who were perceived by children as more warm and responsive to the child’s needs had children who perceived themselves as having a higher quality of life with respect to their illness (Botello-Harbaum, Nansel, Haynie, Iannotti & Simons-Morton, 2008).

The extant monitoring research within the pediatric chronic illness literature does not speak to potentially important aspects of the knowledge acquisition process, such as child disclosure. Child disclosure may be particularly important for effective parental monitoring of chronic illness management, because children may be the only ones who are aware of

illness symptoms. Responding to acute symptoms can be critical for effective and timely disease management. Furthermore, prior research with both general and childhood chronic illness populations has focused on monitoring behaviors during adolescence, with less emphasis on earlier and later phases of development during which monitoring is also likely to be important for both treatment adherence and health outcomes.

Further, there is a lack of descriptive research that explores how parent and child perceptions of child disclosure and parental monitoring behaviors are related to chronic illness management and parent and child reactions to these behaviors. An understanding of parent and child reactions is potentially important, because such reactions may influence how parent-child interactions around chronic illness management, as well as adherence to treatment, evolve over time.

Thus, the primary goal of this qualitative study was to explore how youth with a chronic illness and their parents describe youth disclosure of illness-related information and parent monitoring behaviors related to illness management. The present study sought to address gaps in prior research by: 1) exploring the youth's role in the monitoring process, via disclosure of symptom- and treatment-related information, 2) including both children and adolescents from three different illness groups (type 1 diabetes, asthma, and cystic fibrosis), which allowed us to explore a broad range of potential monitoring and disclosure behaviors related to chronic illness management, 3) describing parent and youth reactions to one another's monitoring-related behaviors, and 4) using qualitative methods in a research area that is dominated by quantitative methods. The use of qualitative methods and a diverse sample in the present study facilitated a rich understanding of how parents and youth interact around illness management on a daily basis. These data add to the extant quantitative literature in the area of parental monitoring of chronic illness management and extend the field through the generation of hypotheses for additional research. Such data can be used to inform the development of new measures of illness-related monitoring and youth disclosure, which has been identified as an important goal for future research (Ellis et al., 2008). Using multiple methodologies can also strengthen previous findings by establishing that diverse methods lead to convergent results.

The overall aim of the broader study on which these analyses are based was to understand parent and child collaborative decision making regarding chronic illness management (Miller, 2009); the findings presented here are also derived from this dataset and focus on behaviors related to parental monitoring and youth disclosure, which emerged as important themes in the data. These themes warranted a more fine-tuned analysis and are the focus of the current report.

Methods

Participants

Participants were identified and recruited between July 2007 and March 2008 from a local diabetes camp, a diabetes family retreat, and the Division of Pulmonary Medicine at a Northeastern children's hospital. Eligible and potentially interested participants were identified by camp/retreat directors and clinicians and were contacted by the second author to solicit participation in the study. If eligible and interested, parents and/or children were scheduled for a focus group or individual interview. Focus groups were the primary method used to collect the data and individual interviews were used only when participants were unable to attend a scheduled focus group and for all youth participants diagnosed with cystic fibrosis because of the need for infection control. Focus groups and interviews were conducted separately for youth and parent participants. Although attempts were made to combine illness types within focus groups to increase the diversity of the groups, this was

not always possible (e.g., at the diabetes camp). Informed consent and permission were obtained from parents, while assent was obtained from youth participants. Participants were each compensated with \$20 following study completion. The study was approved by the institutional review board.

In total, there were 18 children and youth participants (56% ($n=10$) were female) diagnosed with cystic fibrosis ($n=6$), asthma ($n=3$), or type 1 diabetes ($n=9$); duration of diagnosis ranged from 1 to 14 years ($M 9.2$, $SD \pm 4.9$). They ranged in age from 8 to 19 years ($M 12.6$, $SD \pm 3.6$) and were predominantly Caucasian ($n=17$, 94%). Three focus groups ($n=11$) and seven individual interviews were conducted with the youth participants. Of the child and youth participants, 10 had parent(s) who also participated in the study.

In total, parent participants consisted of 16 adults with children and youth diagnosed with cystic fibrosis ($n=6$), asthma ($n=5$), or type 1 diabetes ($n=5$). Parents ranged in age from 33 to 59 years ($M 42.1$, $SD \pm 7.7$); most parents were Caucasian ($n=14$, 88%) and mothers ($n=14$, 88%). Their children's ages ranged from 8 to 17 years ($M 11.1$, $SD \pm 2.4$). The duration of diagnosis ranged from 1 to 17 years ($M 8.2$, $SD \pm 3.8$). One individual parent interview was conducted because only one parent showed up for one of the scheduled focus groups, and five focus groups ($n=15$) were conducted. Eleven of the participating parents had a child who also participated in the study. Additionally, there were two couples in the parent sample¹.

Procedure

An interview template was developed for use with both parent and youth participants in focus groups and individual interviews, to gain an understanding of collaborative decision making for treatment-related decisions. The interview template for parents included the following questions: 1) What decisions come up in the management of your child's illness? 2) To what extent do you involve your child in decisions about treatment? 3) What gets in the way of involving your child in decision-making? What makes it easier? 4) Does your child's involvement change over time? If so, why? 5) What are the benefits and drawbacks of involving your child? 6) Is your child's involvement in decision-making different for decisions not related to chronic illness, such as chores, curfew, and activities? If so, why? Analogous questions were used for youth participants, and follow-up probes were used as necessary.

The second author conducted all of the focus groups and individual interviews. Interviews and focus groups were conducted until thematic saturation was reached (i.e., no new themes were emerging from the data). Data collection took approximately 1–2 hours for each focus group or individual session. Although the interview template was used to guide the discussion, the open-ended and nonstandardized approach to the discussion facilitated the spontaneous generation of themes that were most important to participants. This approach increases the validity of the experiential data (Briggs, 1986; Clandinin & Connelly, 1994). After each focus group or individual interview, the interviewer wrote a memo to document key themes and initial interpretive comments.

Data Management and Analysis Plan

Focus groups and interviews were audiotaped, transcribed and de-identified. The data were then analyzed using the qualitative data management program NVivo (Richards, 1999). An inductive coding approach was used. Initial coding was guided by the interview template;

¹The presence of one of the couples is the reason why 11 parents had corresponding child participants, while only 10 children had corresponding parent participants.

however, as data collection continued and new themes emerged the coding system was updated to reflect growing breadth and depth of the arising themes. All transcripts were coded using the final version of the coding scheme.

Following guidelines for qualitative research, the reliability of the data was addressed by the analogous concept of dependability (Erlandson, Harris, Skipper, & Allen, 1993; Lincoln & Guba, 1985). First, a second coder (first author) was used to code 50% (n= 8) of the transcripts to ensure a systematic application of the coding scheme. Following double-coding, the second author reviewed the results to identify discrepancies in the application of codes to the text. Inconsistencies were resolved through mutual discussion. These discussions facilitated a better understanding and a shared interpretation of the data (Armstrong, Gosling, Weinman, & Marteau, 1997). Second, memos were used to document how codes were determined, how text was interpreted throughout the coding and analysis process, and the questions and interpretive thoughts that arose when discussing the results of double-coding. Furthermore, we kept an audit trail, consisting of recorded materials, interview guides and transcripts, notes about research procedures, and memos, to document data generation, coding, and analysis (Lincoln & Guba, 1985).

Results

First we describe parental monitoring behaviors and youth reactions to these behaviors. This data is followed by a description of how and why youth disclose illness-related information and parental reactions to these disclosures. Illustrative quotes are incorporated in table format Tables 1 and 2) to substantiate and describe key thematic concepts.

Parent Monitoring Behaviors and Youth Reactions

We found that parents use a variety of strategies for obtaining information about their children's regimen adherence, illness symptoms, and other indicators of well being. Both parents and youth reported that parents acquire information by tracking materials related to treatment adherence (e.g., checking inhalers, counting pills, looking for unused test strips) and staying tuned into the presence of illness-related symptoms and behaviors. Not surprisingly, both youth and parents also commented that parents frequently remind or "nag" about treatments and ask if treatment tasks are complete. Additionally, some parents require that children perform treatments in the visual presence of the parent. In this way, parents are able to stay knowledgeable about their children's regimen adherence by directly observing completion of treatment tasks. According to both youth and parents, parents also attempt to control their children's illness by restricting activities that might exacerbate the illness and by using time limits to encourage regimen adherence (e.g., requiring that the child complete a treatment before going outside to play). Parents and youth noted that parents employ a repertoire of strategies in concert to monitor in their child's illness.

Parents expressed a sense of duty, purpose, and responsibility with respect to their role in monitoring their children's treatments. At the same time, parents recognized the need to balance parental control with the child's need for autonomy and ability to manage the illness and treatment regimen. Facilitating treatment adherence, while encouraging independence, appears to be a complicated task and potential source of stress for some families. Parents described a process of adjusting their child's responsibilities for self care activities along with the intensity with which they monitored these activities. In particular, some parents reported that they require their children to "prove" that they can manage their illness management successfully before permanently decreasing the level of monitoring the parents provide (e.g. decreased reminding, and limit-setting). Several parents explicitly noted that adolescence is a particularly difficult time for this "calibration" process.

Youth's reactions to parental monitoring behaviors vary; reactions can range from irritation to ambivalence to appreciativeness. Generally, it appears that youth do not mind their parents' monitoring behaviors, as long as they perceive them to be warranted. For example, youth appear to recognize that parental reminders are helpful and necessary at times. However, youth sometimes perceive parental monitoring as excessive, interrupting, or potentially embarrassing. Youth also reported believing that parental monitoring should decrease as they get older. Participants' comments also suggest that youth respond to parental control attempts in a variety of ways. Responses include complying, complaining, or attempting to change the parent's mind (i.e., persuading).

Youth Disclosure and Parent Reactions

Based on youth participant comments, it appears that youth disclose information freely (i.e., unsolicited by parents), as well as in response to their parents' requests for information. It does not appear that these two types of disclosure are mutually exclusive such that youth only disclose information freely or only when prompted by their parents. Youth described instances of freely disclosing information to their parents for a specific purpose such as to obtain help with a treatment (e.g., counting carbohydrates; whether to take rescue inhaler), to get the parent's opinion, or to have the parent make a decision (e.g. to call the doctor, adjust medication or stay home from school).

Youth also disclose information in response to parental requests for information. Parent requests ranged from informal routine inquiries (e.g., How are you feeling today? What did you eat for dinner?) or may be directly related to a perceived health issue. Overall, youth appear to have confidence that their parents can handle problems by facilitating treatments and helping to make decisions, although some children spoke about waiting until they could not "handle it" by themselves prior to engaging their parents. Parents also commented that the youth sometimes deliberately withhold or minimize the severity of health related information. Common reasons for not wanting to disclose information are to avoid unpleasant treatments or perceived negative consequences and to prevent their parents, usually their mothers, from worrying.

Based on both parent and youth report, parents appear to react to their children's disclosures in a variety of ways. Depending on the perceived severity of the disclosed information, parents might independently make treatment-related decisions, involve the child in decision making, probe for more information using guided questioning, or simply decide not do anything (e.g. wait and see). According to youth, parents sometimes respond with appropriate concern, while at other times they respond by over- or under- reacting to the disclosed information.

Discussion

Using qualitative methods we investigated how parents and youth diagnosed with a chronic illness perceived, described and reacted to both parental monitoring behaviors and youth disclosure of illness-related information. Participants from three different illness groups, as well as both younger children and adolescents, were included in the study sample. By taking care to widen the breadth and diversity of the study sample we were more likely to elucidate a range of themes that might not be apparent had we only focused narrowly on one age group or illness type. This approach is consistent with the principle of maximum variety sampling. The goal is to select a heterogeneous sample so that a range of perspectives is assessed. As such, the sample is not meant to be representative of the population. This sampling technique facilitates an examination of both commonalities and diversity within a varied population (Knafl, Deatrick, & Kodadek, 1982; Morse, 1994). Additionally, the localization of parental monitoring research within illness type makes it difficult to

determine if there are generalized commonalities among parental monitoring behaviors and parent-child interactions that span illness type. The inclusion of multiple illness types allows us to think about theoretical issues more broadly.

Implications of Emerging Themes for Chronic Illness Management

Both parents and youth evidenced a variety of behaviors, feelings and perceptions related to their own and others' attempts to promote youth treatment adherence and to facilitate the transition to youths' independent management of their illness. Within this milieu, a few important issues stood out as particularly relevant for chronic illness management. First, the issue of disclosure came up repeatedly among the participants. There has been some debate in the developmental literature regarding if and why children disclose information to their parents, individual differences in disclosure, and the relative importance of this disclosure to indicators of child and family well-being (Darling, Cumsille, Caldwell, & Dowdy, 2006). The present research suggests that children vary considerably in how much health information they disclose, when they decide to disclose it versus hide it, and to whom they disclose information. Some youth described waiting until they were unable to manage the situation (e.g., worsening symptoms) on their own before disclosing information to their parents. This delay could slow the receipt of important treatments.

Youth disclosure of health-related information may depend on whether or not the information is perceived as residing within the domain of personal versus parental authority. Social domain theory (Smetana et al., 2006; Smetana & Asquith, 1996) posits that parent and youth conceptions of parental authority vary by domain (e.g. personal, prudential, conventional, and moral), and prior research suggests that adolescent disclosure of information varies according to the perceived domain of that information (Smetana et al., 2006). Thus, the way in which youth perceive illness-related information is likely to influence their acceptance of parental control and monitoring (Smetana, 2006; Smetana & Asquith, 1996). Understanding the nature of youth disclosure of health information is vital in light of the role that symptom recognition and responsiveness plays in effective illness management. Of particular interest to practitioners may be furthering our understanding of how youth differentially disclose information related to specific treatments (e.g., chest physiotherapy versus enzymes). For example, a child may be honest and up front about chest physiotherapy treatments but fail to notify the parent about not taking enzymes at school, due to embarrassment about taking the pills in front of classmates. Research related to this issue could be used improve treatment adherence by addressing the specific challenges children and youth may have around specific treatment modalities.

Second, consistent with prior research, (Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997; Palmer, Berg, Wiebe, Beveridge, Korbel, & Upchurch, 2004), parents described a period of adjusting the child's responsibilities for self care activities along with the intensity with which they monitor these activities. Parents described calibrating their involvement based on the youth's maturity and performance. More detailed research into how this calibration process unfolds and relates to health outcomes is needed in order to develop intervention programs to promote interactions that lead to successful illness management. Interventions designed to promote youth disclosure of health-related information in a timely fashion or assist parents with the delicate balance of supporting youth autonomy while avoiding the potential short- and long-term complications of chronic illness are needed. These interventions will need to address parental beliefs (e.g., sense of duty) and emotions (e.g., fear of illness complications; guilt) in order to be effective.

Lastly, the development of measures of both parent monitoring strategies and child disclosure behaviors related to chronic illness management are needed. These measures should separate items related to knowledge from those related to the processes that beget

that knowledge. Measures should include items that assess free disclosure, prompted disclosure, and secrecy or lying related to symptoms and treatment.

Limitations

First, as with all studies conducted with volunteer participants, the subjects in this study may be a highly motivated group and may differ in some unknown way from parents and youth who did not participate. Second, the sample included individuals from several different chronic illness groups, with varying duration and prognosis, and incorporated a broad child age range. While this approach strengthened the analysis by assuring that a range of perspectives was assessed, the study was not designed to make comparisons between age groups or disease groups. In addition, focus group methodology does not allow for the attribution of text to particular individuals, making it difficult to explore if factors such as illness, age, or family structure impacted perceptions of monitoring and disclosure. Third, the sample consisted of primarily Caucasian participants, so generalizations to other ethnic populations are not possible. Similarly, as with most research, families who agreed to be part of the study may differ in important ways from participants who did not agree to participate.

Conclusion

The present study adds to the growing body of “monitoring” literature in pediatric health psychology and, we hope, serves as a jumping off point for other researchers interested in investigating monitoring in chronic illness populations. By qualitatively exploring what parents and youth say about how they interact around illness management, we were able to identify aspects of parental monitoring and child disclosure that are unique to the context of chronic illness, examine parent and youth potential reactions to each other’s behaviors, and explore how these interactions may evolve over time.

Key Messages

1. Management of a childhood chronic illness can be challenging because it can involve frequent and complex treatment tasks that must be carried out on a daily basis.
2. Children vary considerably in how much health information they disclose, when they decide to disclose it versus hide it, and to whom they choose to disclose.
3. Quantitative measures of child chronic illness management should include items that assess youth free and prompted disclosure of health information as well as omission and lying about this information.
4. Youth-directed interventions for children diagnosed with a chronic illness should focus on the promotion of the timely disclosure of health-related information.

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Table 1

Parent Monitoring Strategies and Youth Reactions

Emerging Themes	Illustrative Quotes
Monitoring - Surveillance	<p><i>Parent Participant:</i> So, I'm getting pretty good at noticing his symptoms so ... anything that triggers it, I'm always keeping my eye out.</p> <p><i>Parent Participant:</i> I mean with [child's name], sometimes the pills, a couple of times, they've been left behind You know, you're trying to get to the bus or whatever, and ... you look in the pill cup, and then it's like still there.</p>
Monitoring - Control Through Restrictions and Observation	<p><i>Parent Participant:</i> But one thing that we do before we go out and buy some ice cream or whatever ... somebody will mention ice cream, and we'll say, "No. First you've got to check your blood sugar," and that way, we start right off the bat.</p> <p><i>Youth Participant:</i> Well, like I said, they usually watch me do it, to make sure I take the right amount.</p>
Parental Sense of Duty and Purpose	<p><i>Parent Participant:</i> "...you know, part of what I'm doing is what I'm supposed to do as a parent. I'm supposed to monitor this stuff. I'm the one who is.</p> <p><i>Parent Participant:</i> So, I can't fool around letting him screw off or screw up. I can't, I can't do that. It's just not responsible as a parent to, to do that.</p>
Balance of Control and Youth Autonomy	<p><i>Parent Participant:</i> I certainly want to have reasonable expectations, for him, as he transitions and does this independently. It's a dance again in that way, and we'll see how it goes, you know?</p> <p><i>Parent Participant:</i> She's not doing the checking, not doing this, getting lazy. You're checking the meter and the pump, and they're not jiving, that kind of thing. So that's when we grab hold and take control again.</p>
Youth Irritation with Parental Solicitation	<p><i>Youth Participant:</i> My mom will ask me if I bolused right exactly when I have the food in my hands, so then if I didn't, I'd have to put the food down, and I'd have to bolus, and it's really just a big hassle.</p> <p><i>Interviewer:</i> Oh, your mom gets on you?</p> <p><i>Youth Participant:</i> It's gotten to the point that my mom nags me so much that one of her best friends nags me about it too.</p>
Youth Acknowledgement of Parental Role	<p><i>Youth Participant:</i> Like, sometimes, I'll get a little bit upset because I'll really, really want something, and then they're like, "But your blood sugar is still high." And ... I just want to scream because I really want it that bad. But then I realize, well, I'm just going to feel so much worse if I have it, and then I realize that ... whenever I want something and she's saying no, I can admit it, she's always right.</p> <p><i>Youth Participant:</i> It used to be two puffs of Flovent twice a day, then it was four, now it's six, so they've got to help me make sure I'm doing the right amount.</p>

Table 2**Youth Disclosure and Parent Reactions**

Emerging Themes	Illustrative Quotes
Youth Disclosure	<i>Youth Participant:</i> It's usually just giving him a heads-up that I'm starting to not feel so good. It might be just because I need to ask him a question like, "My chest is bothering me and I'm having a tough time breathing. What do you think that is?" I just need his input basically, like, if I should be worried about it. Because if he's not worried about it, then I'm not going to be worried about it.
Youth Non-Disclosure	<p><i>Youth Participant:</i> I usually wait to tell her until the last second when I don't feel good ... And ... whenever I really can't handle it by myself, that's when I tell them.</p> <p><i>Youth Participant:</i> It's annoying to be on a lot of medication that tastes disgusting, and if I know it's going to pass, then I'll just kind of ignore it and not tell them about it.</p> <p><i>Parent Participant:</i> I notice. I notice. I notice. She don't, she don't come to me too much because she tries to be strong, but I can just see the activity level and I would just look at her and tell she's not feeling well instantly. And I ask her, and she says, "I'm okay," but then, later that day, I'll go, "Are you okay?" and she'll say, "Well, I'm wheezing just a little bit," and then slowly, gradually, and she'll just say, "Mom, I just, I don't feel well. I can't take it. I can't do it no more." And that means it's time to go.</p>
Parental Reactions to Youth Disclosure	<p><i>Youth Participant:</i> It's not good when they overreact to something that you say.</p> <p><i>Interviewer:</i> Can you give me an example?</p> <p><i>Youth Participant:</i> Well, I'll be like, "I was coughing a little bit of stuff up at school today," and they'll be like "Oh, do you need to do this? Do you need to do that?" And it's like, "No, that's not what I said. I said I just coughed something up."</p> <p><i>Youth Participant:</i> If I start to feel a cough, I'm just like, "Oh, it's just a cough. I'm fine." So, I'll just adapt to it, but usually, ... I'll tell my dad, just because he gets less upset about it, where if I tell my mom, she's like calling every doctor –</p>