

# Emotional and Behavioral Changes in Parents of Children Affected by Hemolytic-Uremic Syndrome Associated With Verocytotoxin-Producing *Escherichia Coli*: A Qualitative Analysis

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**Background:** *The long-term clinical outcome for children affected by hemolytic uremic syndrome associated with verocytotoxin-producing Escherichia coli (VTEC-HUS) is well documented, but the parental experience is not.* **Objective:** *The authors investigated the effects of the critical-care hospitalization for this condition on well-being of patients' families.* **Method:** *A group of 30 parents completed a free-response format survey when their child presented to the hospital; 19 of this cohort completed a 1-year follow-up.* **Results:** *Content analysis demonstrated that this cohort of parents experienced long-term emotional distress and substantive disruption to family and daily life.* **Discussion:** *These results corroborate anecdotal clinical observations. The authors suggest future research initiatives and best practices to reduce parental distress.*

(Psychosomatics 2009; 50:263–269)

Hemolytic uremic syndrome (HUS) is one of the most common causes of acute renal failure in childhood worldwide.<sup>1</sup> Patients experience long-term renal impairment sometimes many years after illness, and the determinants of long-term outcomes are unclear.<sup>2,3</sup> HUS is a subset of thrombotic disorders that are caused by several infectious agents, the most common being verocytotoxin-producing *Escherichia coli* (VTEC), such as *E. coli* O157.<sup>4</sup> Clinical surveillance for HUS is particularly relevant in Scotland, because higher rates of infection with VTEC are consistently reported there, as compared with other parts of the U.K. or Europe. Although infection with this organism is relatively rare, HUS can have serious consequences.<sup>5</sup> Furthermore, VTEC is highly infectious and has been responsible for large outbreaks worldwide.<sup>5,6</sup>

Progression to HUS occurs in about 10%–15% of cases infected with VTEC.<sup>4</sup> Most cases are in children

under 10 years old. Although, in most cases, renal function improves, patients often must undergo kidney dialysis; they can experience chronic renal failure, and, in some instances, require kidney transplantation. Follow-up studies have produced conflicting results with regard to renal outcome after an episode of VTEC-HUS,<sup>6–9</sup> but extra-renal sequelae, including psychological problems, have been reported (Schoettle UC, et al: Psychiatric, neurological, and forensic problems in *E. coli*-caused hemolytic uremic syndrome: trauma and recovery. Unpublished; 2002).

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Although the long-term clinical outcome for children affected by VTEC–HUS has been well studied, how parents deal with an affected child has not. However, research on other acute, chronic, and life-threatening pediatric illnesses suggests that dealing with a child's severe illness is associated with increased emotional distress, posttraumatic stress disorder, and depression.<sup>10–16</sup> It has also been recognized that the critical-care hospitalization necessary in such conditions has adverse effects on the nonphysiologic well-being of patients' families.<sup>17</sup> Although there are no studies examining parental reactions to VTEC–HUS specifically, research into the impact of other pediatric illnesses suggests that parents of VTEC–HUS-affected children could experience distress and major upheaval in family functioning. Indeed, clinicians in charge of VTEC–HUS-affected children anecdotally report that parents of previously-healthy children can become very distressed. The fact that dialysis may be required can bring parents even more anguish. Indeed, research suggests that there are adverse effects on the psychosocial and socioeconomic well-being of parents as result of their child's end-stage renal failure and a lower quality of life during a child's chronic peritoneal dialysis.<sup>18,19</sup> Not only do parents have the primary episode to contend with, but also, in rare instances, may have to deal with a transplant procedure in the event of non-reversible, chronic renal failure. Repeat visits to hospital clinic for kidney-function tests may reassure parents in the short term, but the legacy of VTEC–HUS and the possibility of HUS relapse and potential for reinfection are ever-present. Moreover, it is likely that a parental act, such as offering contaminated food to a child or allowing a child to take part in a "risky" activity such as visiting a petting zoo, led to the infection. Such factors can be considered on-going stressors, but how parents feel about these and deal with them has not yet been determined.

In 1997, after a large outbreak of *E. coli* O157 in Scotland that resulted in 512 cases of infection and 17 fatalities,<sup>5</sup> the charity HUSH (Hemolytic Uraemic Syndrome Help), was founded. HUSH representatives were invited to participate in to a national HUS steering group, which includes five clinicians who regularly treat HUS patients, two representatives from HUSH, one consultant in public health medicine, one member of the Scottish Executive Health Department, and two epidemiologists.

This group produced a Patient/Parent questionnaire to assess the psychological impact of VTEC–HUS on sufferers and their parents. To our knowledge, this is the first

study to assess the emotional and behavioral sequelae in parents with children who have had VTEC–HUS.

### METHOD

Ethical approval was obtained via the Multi-Research Ethics Committee for Scotland, whereby permission was granted to investigate the parental experience of dealing with a VTEC–HUS-infected child. The HUS Steering Group designed the study information sheet, consent form, and questionnaire. The questionnaire was piloted with three patients' families, and the families were asked for their opinion of the questionnaire and whether it was easy to follow and/or should be modified.

From 2003 to 2005, cases of pediatric VTEC–HUS (patients under age 15) were ascertained prospectively from an active, ongoing national surveillance program. Clinicians caring for VTEC–HUS patients approached their parents to seek consent for enrollment into the study when they deemed the child was clinically stable. Parents of children affected by VTEC–HUS were given a study information sheet, a consent form, and a questionnaire. They were informed that they could complete the questionnaire and consent form on their own time, either at home or in a private room during their stay at the hospital. Once consent was obtained and forms were completed, the documentation was returned to Health Protection Scotland, and the data were entered into an EpiInfo (Version 6) database. The family general-practitioner (GP) was informed of the patient's enrollment in the study, and a GP information sheet was provided. The GP was also provided with the study coordinators' details if they had questions concerning the study. However, the GP did not see any of the participants' responses. This assured participant confidentiality.

### Questionnaire

The initial survey contained six open-ended questions and was given at the time of admission to the hospital renal unit. It asked for details and commentary on the type of information and advice provided at the time of diagnosis and treatment and the impact of the illness on the child's health and the household in general. Thus, Question 1 asked, "Please describe briefly what type of information or advice you were given." Question 2: "Please tell us whether you think the information or advice was helpful and sufficient." Question 3: "Please tell us what information or advice you think would have been helpful."

Questions 4: "If you feel this has affected your health, please describe briefly how you think your health has been affected." Question 5: "Do you feel that other people in the family or household have been affected as a result of this illness? If so, how?" Finally, Question 6 asked: "Is there anything else you think we should know?"

The 1-year follow-up survey contained eight open-ended questions and was distributed 1 year after initial presentation to the hospital. It contained questions pertaining to the status of the afflicted child's health and whether visits to doctors and ongoing hospital treatments were still needed. It also asked for parents to comment on the information provided and to assess the impact of their child's illness since the initial presentation to the hospital. Question 1 asked: "Do you feel your child's general health has been affected as a result of the illness 1 year ago? If yes, how?" Question 2: "Is there anything your child has stopped doing or felt unable to do since the illness 1 year ago? If so, what?" Question 3 asked: "Have you needed to continue seeing your family doctor about problems associated with your child's illness from 1 year ago? Please state if so." Question 4 asked: "Has your child continued attending the hospital for treatment or follow-up due to the illness 1 year ago? Please give details." Question 5 asked: "Has the illness from 1 year ago had any effect on other members of your household or family? Please give details." Question 6 asked: "Have you been given any information or advice about the illness from 1 year ago? Please give details." Question 7 asked: "If you did not receive any information or advice, or if you would have liked more information or advice that you did receive, please say what." The final question simply asked if there was any other helpful information that the research team should know.

#### Data Analysis

Content analysis was performed on the written free-responses to each question from both the initial-onset and the follow-up questionnaires. Methodologically, it is acceptable to use a sampling strategy to reduce content analysis to a more manageable task. Thus, one can draw on a representative sample of the responses given by participants. However, with only 14 response items per parental dyad/single parent, the authors decided to subject all responses from all parent(s) to content analysis.

To establish recurring themes or categories across all questions and each survey, the two lead authors independently read through all responses. Each author indepen-

dently identified examples of manifest content (individual words or whole items) as well as latent (high-inference) content from this initial reading.<sup>20</sup> The authors met to discuss recurrent themes and exemplars. Any disagreement about placement of exemplars was discussed and resolved. A further reading of all cases was performed, ensuring that instances of latent content were included, although the use of this high-inference strategy was kept to a minimum. This second analysis resulted in two themes from one assessor being merged into one new and broader theme. As a result of these two iterations, five themes were finally identified.

#### RESULTS

The parent or parents of 32 cases of pediatric VTEC-HUS were approached and informed about the study. Thirty (93.75%) agreed to complete the initial questionnaire. These initial-stage respondents were also asked to complete the 1-year follow-up, and 19 (63%) of this group did so. The other 11 were not completed either because they refused ("just wanting to forget about the experience" often reported) or they had moved from their previous address and could not be contacted. Twenty-nine mother and father dyads and one single parent (mother) made up the initial cohort of 30. The follow-up consisted exclusively of mother/father dyads. It is interesting to note that it was predominantly mothers who completed the questionnaires at each stage (28 of the 30 respondents at the initial stage and 17 of the 19 at the follow-up stage).

From the content analysis, the following five recurrent themes were identified: 1) emotions and psychological distress; 2) impact on daily behavior; 3) fear of the future, 4) illness etiology; and 5) judgment of care/information given.

Mindful of space restrictions and the focus of the study, only the first three themes will be examined here. Table 1 shows the verbatim exemplars extracted from the free-responses. The narrative following the table expands each theme and provides actual quotes from respondents as illustrations.

#### Theme 1: Emotions and Psychological Distress

These parents reported experiencing intense negative emotion. "Anxiety," "anguish," "feeling under unnecessary pressure," "paranoia," "stress," "physical and mental exhaustion," "trauma," and "clinical depression" were just some of the words used by parents to describe how they

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were feeling. Moreover, this intense negative emotion was evident at both initial and follow-up periods. One parent wrote that “We had to attend hospital appointments (time off from work; sometimes stressful when blood-drawing involved). [The] patient’s mother has been clinically de-

pressed; the stress of the illness and continuing worries may have contributed.” Similarly, another respondent wrote, “Speaking for [the] patient, dad, and myself, everything has changed. We are in a routine now, but a very different one. You try to put on a brave face but the stress

**TABLE 1. Verbatim Exemplars Extracted From Questionnaire Responses**

Recurring Themes (Initial Survey Responses / 1-Year Follow-Up)		
1. Emotions/Psychological Distress	2. Behavior and Daily Routine Changes	3. Fear of the Future
Stress	Siblings out of routine	Re-infection fear
Paranoia (over re-infection)	Increased vigilance over children	Relapse fear
Pain	Ongoing check-ups	<i>New symptoms connected to HUS?</i>
Anxiety	Daily routine changes	<i>Looking for long-term reassurance</i>
Concern for others	Now feel under pressure generally	<i>Fear of future illnesses</i>
Angry with GPs	Very strict toilet regime	<i>Need to know more about future</i>
Frustrated	Logistical problems in being moved to other hospitals	<i>Possible long-term problems</i>
Exclusion	Child became obsessive-compulsive	<i>Continue with concerns over health</i>
Trauma	Eating habits changed	<i>Apprehensive re: future treatment</i>
Anguish	Impact on other children	
Worry	Other childrens’ behavior changes observed	
Unhappy	Work-routine changes	
Happy	Daily peritoneal dialysis	
Hate	Parents away from home	
Reassurance	Changes to food/diet	
Unnecessary pressure	Others out of routine	
Positivity of care	Worry for other members of the family	
Psychological trauma	<i>Compares child to others</i>	
Mentally exhausting	<i>White Coat Syndrome</i>	
Confusing	<i>Move to urban area</i>	
<i>Terrified</i>	<i>Wary about hygiene</i>	
<i>Anxiety</i>	<i>Advice re: food/nutrition</i>	
<i>Scared</i>	<i>Stopped working</i>	
<i>Alarming</i>	<i>Watchful of new illnesses</i>	
<i>Stressful</i>	<i>Vigilance</i>	
<i>Apprehensive</i>	<i>Withdrawal from previous suspected environments</i>	
<i>Worry generally and over future</i>	<i>Everything changed</i>	
<i>Matter-of-fact/objective, non-emotional</i>	<i>Moved away from rural area</i>	
<i>Keeping things in perspective</i>	<i>Time off work</i>	
<i>Panic</i>	<i>Regular check-ups</i>	
<i>Positivity of care</i>	<i>Checking food products</i>	
<i>Blame</i>	<i>Plans to alter medication</i>	
<i>Guilt</i>	<i>Wary about petting animals</i>	
<i>Reassurance</i>	<i>Concerns over hygiene habits</i>	
<i>Unnecessary pressure</i>	<i>Everything has changed, to be planned; no spontaneity</i>	
<i>Relief</i>	<i>In routine now</i>	
<i>Depression</i>		
<i>Psychological and emotional impact on mother</i>		
<i>Coping levels stretched</i>		
<i>Long term emotional upset</i>		
<i>Hope (crossed fingers)</i>		
<i>Clinically depressed</i>		
<i>Crying</i>		
<i>Upset</i>		
<i>Distressed</i>		
<i>Delighted</i>		
<i>Wary</i>		
<i>Cuddle</i>		

Items in italics recurred at 1-year follow-up.

and tiredness is very hard to hide. A good cry is often helpful, and a cuddle.” Another respondent summarized the ongoing distress by writing “We have aged 10 years.”

There were only five instances of positive-emotion words and/or actions reported (“reassurance,” “hope,” “relief,” “delighted,” and “cuddle”). These were evident only in the follow-up survey and were dependent on a child’s making significant progress. In contrast, two respondents were notable for a description only of their child’s clinical outcomes and the absence of emotive language. Lack of emotion or emotional numbing can occur in the immediate aftermath of a traumatic life event.<sup>21</sup> However, without a standardized self-report scale or objective measurement of these parents’ reactions, we cannot speculate on whether absence of emotion in our own sample is indicative of temporary pathology.

### Theme 2: Impact on Daily Behavior

All parents and their siblings experienced major changes in daily routine. Hypervigilance over children, changes in eating habits, and strict control over hygiene were the norm. The burden of daily care/treatment and logistical demands of ongoing hospital visits all had an impact on daily life. Parents also expressed concern for the impact of changes on other members of the family, as well. There was evident concern that other siblings were missing out on the usual parental care because one of the parents had to be away from home to be near the hospital. Parents also wrote that they frequently compared their children with others in terms of general behavior and health status. Absence from work and/or giving up work and moving away from rural residences exemplify profound change in circumstances. One parent wrote that “I do keep a mental note of her daily toilet habits,” and another commented that they were “more wary about cleanliness and petting animals.” Another statement typifies this theme: “When on 10 hours of nightly dialysis and feeding, everything changes—school, hobbies (no swimming), and general activities change. Everything has to be planned—there’s no spontaneity.” This respondent shows that preventing reinfection is of paramount importance: “Still affected badly by the experience. Unwilling to allow ‘X’ to have any contact with farm animals. The family have decided to move away from [a] rural area.”

### Theme 3: Fear of the Future

Parents reported “fear” and “paranoia” about reinfection and/or relapse of HUS, general fear of new illnesses

and symptoms, possible long-term ramifications, and the desire to know more about future outcomes. This is exemplified by the quote “Suffer from anxiety, not knowing how my daughter was going to pull through, depression, and, also, fear in case she falls ill again and HUS recurs again.” The need for more information at diagnosis and fear for the future for their child was raised by a majority of respondents. The uncertainty about future consequences, lack of control, and fear of not being careful or vigilant enough were the preoccupations of these parents now. These fears echo those found in other studies of parents dealing with a chronically ill child.<sup>22</sup> With respect to other chronic illnesses in childhood, it has been shown that parental uncertainty is related to psychological distress.<sup>22</sup> Thus, parents are vulnerable to the experiences of ongoing anxiety, cognitive disturbances, and helplessness.

## DISCUSSION

Much is documented about the long-term clinical outcome of children affected by VTEC–HUS, but the impact on parents of afflicted children has not been documented. This study is unique in that it sought to explore the effects of VTEC–HUS on parents. It did so by the administration of surveys at both initial hospitalization and at 1 year thereafter. The inclusion of a 1-year follow-up was important to establish the temporal course of adjusting to an infected child. A qualitative analysis of all responses was carried out in order to ascertain whether clinical observations of parental distress could be corroborated. This content analysis demonstrated that intense emotional distress was commonplace at the 1-year follow-up, demonstrating that emotional strain is present long after the acute phase of the child’s illness. The finding that fear of unknown long-term repercussions, relapse, and reinfection were still causing distress and rumination 1 year later suggests that dealing with an infected child is a chronic stressor. The term the “living worried,” adopted by Monsen in a qualitative study of parents whose children have spina bifida<sup>23</sup> would seem to be appropriate to use to describe our own cohort of parents. The recurring themes of emotional strain, daily life changes, and ongoing struggle to monitor the children and the concern about future health status are similar to those detailed in a recent metasynthesis on parenting a child with a chronic illness.<sup>24</sup> Our study provides evidence that systematic observation is necessary for parents whose well-being may be at risk.



## Limitations of the Study

There is, to our knowledge, no other study examining the impact of VTEC–HUS on parents. Because of this, we cannot validate our results with previous studies in this area, and we therefore see these results as preliminary. We must acknowledge that these are preliminary findings from a free-response format survey, and, as such, they do not provide indications of actual stress or any other emotional pathology. However, the findings do corroborate clinical observations (and personal communication with the Secretary of HUSH). It is, of course, important to point out that these experiences may not represent those in other cohorts of VTEC–HUS children and parents. This should not, however, invalidate the level of distress reported in this study. The fact that distress is evident at 1 year after diagnosis should prompt concern for those dealing with parents of infected children.

## Recommendations and Future Research

We need to extend these preliminary findings with more systematic measurement of psychological sequelae of VTEC–HUS on parents. To do this effectively, we suggest a measure of stress-related symptomatology such as the Posttraumatic Diagnostic Scale (PTDS).<sup>25</sup> This 17-item scale measures the presence and level of such things as avoidance, reexperiencing, arousal, reduced interest, and sleep difficulties. Since a plethora of studies show that family functioning is a predictor of the psychological functioning of a child with a chronic illnesses,<sup>22</sup> it may be prudent for future research to include a measure of family functioning. For example, a recent study of parents whose children had brain tumors showed that the Parent Experience of Child Illness (PECI) scale was effective in assessing the degree of parental adjustment and that it had good reliability.<sup>26</sup> Also, a measure of personality and individual differences such as the State–Trait Anxiety Inventory (STAI)<sup>27</sup> would identify those most at risk for developing

stress-related pathology and who, thus, may require psychosocial support. Future studies should also seek to redress the paucity of data from fathers in this area.

Although incidence rates of VTEC–HUS are lower than those of other pediatric conditions, this does not mean that support and resources should be minimal. Arguably, its rarity makes it even more necessary to provide accurate information and support to parents, so as to stem increases in distress. Our cohort reported extremely variable experiences in the amount and quality of information provided by nurses and other healthcare providers. Intervention studies in other areas of pediatric medicine demonstrate that information and diagnosis management are crucial to parental coping.<sup>28–30</sup> The authors suggest a coordinated approach between general practitioner, pediatricians, and HUSH to alleviate parental concerns, where possible.

Confirmatory results should prompt consideration of a cost-effective, logistically feasible intervention to alleviate such parental distress. It is worth noting that an intervention involving several problem-solving sessions reduced negative affectivity in mothers whose children had recently been diagnosed with cancer.<sup>31</sup> It could be that interventions targeting behavioral and cognitive processes may be effective in helping parents cope with the advent of a VTEC–HUS-afflicted child. We also suggest that parents who are members of HUSH and have thus gone through a similar traumatic experience be invited to become mentors for those parents with a newly-infected child. The development and efficacy of such a support scheme would need to be fully evaluated from both the support-provider and the receivers' perspectives.

In conclusion, this study has highlighted the difficulties undergone by parents coping with a VTEC–HUS-infected child. Although the findings should be regarded as preliminary and, in the main, reflect how mothers feel, they do warrant further systematic investigation and development of possible intervention strategies.

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