Objective: To evaluate the psychosocial status of mothers and fathers of infants with hypoplastic left heart syndrome while in the PICU.

Design: A retrospective study combining interviews and psychometric testing of parents.

Setting: Tertiary hospital PICU.

Subjects: Twenty-nine parents (16 mothers and 13 fathers) of surviving children.

Intervention: A semistructured face-to-face interview was conducted to explore parental experiences, and a Structured Clinical Interview for Diagnosis-Clinical Version (posttraumatic stress disorder module) was conducted to determine the possibility of an acute stress disorder or a posttraumatic stress disorder.

Measurement and Main Results: All parents reported multiple stresses which commenced with their infant’s diagnosis and endured throughout their infant’s time in PICU. The Structured Clinical Interview for Diagnosis revealed that acute stress disorder or posttraumatic stress disorder developed in 24 parents (83%). Of 18 parents whose infants were diagnosed with hypoplastic left heart syndrome in utero, eight of nine mothers (88%) and six of nine fathers (66%) had posttraumatic stress disorder. Of 11 parents whose infants were diagnosed with hypoplastic left heart syndrome postbirth, six of seven mothers had acute stress disorder and one mother had posttraumatic stress disorder, and of four fathers, two fathers had acute stress disorder and one father had posttraumatic stress disorder. The prevalence of parental stress-related disorder was not different between mothers and fathers (p = 0.85). Only five parents were free of traumatic stress-related illness. Parents also experienced losses. Many parents were marginalized from their infant’s care by the environment of PICU. Fifty percent of mothers experienced difficulties with parental-infant bonding. Ten parents (34%) began the process of adaptation to their infant’s hypoplastic left heart syndrome and were assisted by the support and sensitivity of staff or had discovered other resources.

Conclusions: All parents of surviving infants with hypoplastic left heart syndrome in PICU, irrespective of timing of diagnosis, experienced numerous stresses and losses, and the majority exhibited clinical levels of traumatic stress. Receiving the diagnosis itself is very traumatic and is compounded by the environment of the PICU which alienates parents from their infants and interferes with parent-infant bonding. Parental adaptation to this situation can be assisted by staff. (Pediatr Crit Care Med 2013; 14:869–875)

Key Words: acute stress disorder; adaptation; hypoplastic left heart syndrome; intensive care; parents; posttraumatic stress disorder; psychological; stress

Palliative staged reconstructive surgery has radically altered the outcomes of infants born with hypoplastic left heart syndrome (HLHS) (1), but it still presents great challenges. Although many studies describe the management and outcomes after staged surgery for these infants (2, 3), few studies exist of the experiences of their parents (4–6). This is a study of the experiences of parents of children surviving with HLHS.

Parents of infants in PICU are subjected to numerous psychological stressors which may interfere with bonding and attachment to their infants. The necessary removal of infants from their mothers shortly after birth is an obvious maternal stressor. In addition, parents are often overwhelmed by the PICU environment and commonly associate it with “a massive array of traumatic stimuli” (7).

Admission alone to PICU is perceived by parents of critically ill children as associated with death and morbidity. Those perceptions induce high levels of anxiety (8, 9), sadness, and anger (4, 10). The alien nature of the PICU comprises bright lighting, technological equipment (9, 10), distortion of the child’s appearance (8, 9), invasive medical procedures (10, 11), mechanical ventilation (12), witnessing other difficult sights (10), difficulties with staff including poor communication and insensitivity (13), and the child’s sedation and neuromuscular blockade.

Although the prevalence of posttraumatic stress disorder (PTSD) among parents of children with HLHS is unstudied, it occurs among parents of children with other serious
illness (12). Traumatic stress occurs in parents whose child is newly diagnosed with a serious illness (14) (MC McCarthy, Identification of psychosocial risk and traumatic stress in parents of children newly diagnosed with cancer, unpublished doctoral dissertation, University of Melbourne, Melbourne, Australia, 2010), after open heart surgery (15), after accident or injury (16, 17), with cancer (18), diabetes type 1 (14), and congenital disease (19). It occurs in parents whose child has been admitted to a PICU (20, 21). In a review, 71% of parents of children with a serious medical condition had significant levels of traumatic stress symptoms (14).

Parents of seriously ill infants also experience losses. They are deprived of normal parental authority resulting in a compromised relationship with their infant (8, 22) (G Rempel, Parenting a child with HLHS whose infant includes the Norwood surgical approach, unpublished doctoral dissertation, University of Alberta, Edmonton, Canada, 2005). They may be unable to nurture (23) and experience many barriers to the formation of intimacy with their infant (4, 24, 25), including the constant presence of staff at their child’s bedside (10, 22), an absence of effective communication (22), and the child’s sedative medication. These interventions can impede communication and impact negatively on the parent. As a result of these many barriers, parents feel marginalized (8).

Although little is known about the adaptation of parents to their infant’s illness in PICU, it may be facilitated by a range of supportive professional interventions. These include support and reassurance by medical and surgical staff (G Rempel, Parenting a child with HLHS whose infant includes the Norwood surgical approach, unpublished doctoral dissertation, University of Alberta, Edmonton, Canada, 2005) and a recognition of their parental love (26). Positive communication strategies by staff involve openness, patience, approachability, and sensitivity (27), combined with attitudes of regard, concern, kindness, and care, while at the same time fostering realistic hope (13). Parents have also reported helpful personal strategies including self-education about HLHS (G Rempel, Parenting a child with HLHS whose infant includes the Norwood surgical approach, unpublished doctoral dissertation, University of Alberta, Edmonton, Canada, 2005), attitudes of optimism, and the use of cognitive coping strategies that lower stress levels (28).

An understanding of the parents’ experiences in the PICU is important because positive or negative parental experiences at these times may impact on the parents’ health or even impact on their relationship with their infant. Difficulties for parents, arising in PICU, may continue well after their child’s discharge (11, 16, 27, 29–32). The aim of this study was to investigate the parents’ psychosocial status in the PICU.

METHODS

Design and Participants

This mixed methods study combined retrospective narrative interviews with psychometric testing of mothers and fathers after their infant’s first admission to the PICU. Potential participants were identified from PICU records of infants who had had a stage I (Norwood) repair of HLHS between 1983 and 2004. Parents of surviving children who lived in the State of Victoria, Australia, were invited to take part in the study by letter and subsequently by telephone, if they had not responded. Six couples decided not to participate, two fathers were not involved with the child and not interviewed, and one father declined to be interviewed “because it would be too emotional.” The group of respondents consisted of 16 mothers and 13 fathers. Consent included permission to audiotape interviews. At the time of the study, all children had been discharged home. Data were collected between April 26, 2005, and June 18, 2005, after all children had been discharged home. Approval for this study was granted by the Institutional Human Research Ethics Committee.

Interviews

Parents were interviewed once at the location of their choice by the first investigator, a psychologist, who had not been involved in the care of the infants or their parents. Interviews were semi-structured and explored stressors, traumatic stress, losses, adaptation of the parents, and their relationship with their infant.

Table 1 shows the ages of the children, their duration of admission to PICU, and the range of intervals between the infants’ first stay in the PICU and the interview of their parents.

Data Analysis

The interview data of individual parents were subjected to the analysis of themes within the interviews, as identified by Liamputtong and Ezzy (33). The Structured Clinical Interview for Diagnosis (SCID) results were obtained using SPSS 17.0 version (Chicago, IL) (34). The thematic analyses of the interviews were then compared with the test results, and the two methods were combined to form the perspectives on the parents’ experiences.

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<th>TABLE 1. Ages of Children and Duration of Time in PICU</th>
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Psychometric Traumatic Stress Testing

The PTSD module of the Clinical Version of the SCID (SCID-CV) (35) was administered to test for an acute stress disorder (ASD) or a PTSD. The SCID test is an instrument that assesses criteria for ASD (Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition-Text Revision [DSM-IV-TR] code 308.3) or PTSD (DSM-IV-TR code 309.81) as defined by the American Psychiatric Association (36). It assesses frequency and resolution over time of traumatic stress disorders and identifies both current and retrospective traumatic stress. The completion of the SCID-CV test takes 10 minutes or less and requires clinical judgment by the interviewer. It is not a stand-alone psychometric test. If a traumatic stressor has not been experienced, the test is terminated.

The SCID test evaluates clusters of symptoms grouped into criteria. All symptoms in all criteria must be positive to qualify an individual for a diagnosis of ASD. Criterion A: The subject has experienced, witnessed, or has been confronted with an event that involved actual or threatened death or serious injury to self or others and this event evoked strong feelings of fear, helplessness, and horror. Criterion B: While experiencing or after experiencing this event, the subject has experienced dissociative symptoms (numbing, detachment, or absence of emotional responsiveness). Criterion C: The traumatic event is persistently reexperienced. Criterion D: Stimuli that evoke recollections of the trauma are avoided. Criterion E: Symptoms of anxiety or arousal exist. Criterion F: Significant distress or impairment in living exists. Criterion G: The disturbance lasts for a minimum of 2 days and a maximum of 4 weeks. Criterion H: The disturbance is not due to the physiological effects of a substance abuse or to a general medical condition. The criteria for PTSD are similar, but the subject must have symptoms for more than 4 weeks.

In PICU, a parent may have PTSD if their symptoms had not resolved since their infant's diagnosis of HLHS at 20 weeks' gestation. If the diagnosis was made after birth, a parent may potentially have ASD, but to qualify for PTSD, their infant must be present in PICU for longer than 4 weeks. The SCID was administered at the end of the interview.

RESULTS

Sixteen mothers and 13 fathers (comprising 13 couples) were interviewed and were psychometrically tested. The mean duration of admission for their 16 infants in the PICU was 13.7 days (sd, 9.9 d). Fourteen infants were in PICU less than 4 weeks. Twenty-five parents were interviewed at home, and four parents were interviewed in hospital. Five couples were interviewed together because their understanding of English was limited and they needed assistance from each other, whereas the remaining parents were interviewed separately. Duration of interviews ranged from 20 to 90 minutes. The combined findings are categorized as stressors, traumatic stress and stressors, losses, parent-infant relationships, and adaptation.

Stressors

Parents reported multiple stressors in the PICU. The six themes that emerged were 1) receiving the diagnosis of HLHS, 2) the environment of the PICU, 3) their infant's health status, 4) their infant's appearance after surgery, 5) relationships with staff, and 6) family stressors.

Regardless of the timing of the diagnosis, all parents were distressed. HLHS was not diagnosed until after the birth in seven of 16 infants (44%), even though all mothers had had ultrasound examinations during their pregnancies. Parents who were unaware of their infant's diagnosis before their birth had the added stressors of whether to proceed with surgery and of making family arrangements. The latter was particularly burdensome for the five rural families.

The PICU environment was frightening for all parents. Eleven parents said that they feared that the infant would not recover, two parents worried that serious complications might develop in their infant, and two parents worried about their infant's future. Eight parents spoke about stressors related to insensitive or inadequate communication from doctors. These included excessive emphasis on the hardship for parents generated by the diagnosis and poor prognosis of their infant. Parents also cited poor interpersonal skills, lack of empathy, or inadequate provision of information from staff. No parent had had a comprehensive conversation about palliative care at the time of the diagnosis or in the PICU. Two parents spoke about their difficulties with nurses, for example, insensitive comments.

The infant's stay in the PICU disrupted family life. All mothers stayed with their infant in the hospital and dealt with hospital stressors, while fathers were strained by long travelling distances to hospital, home, and work and experienced disruptions to routines. Partners were separated from each other, and mothers were separated from their other children. Five parents were physically exhausted, and 22 parents experienced financial difficulties due to travel and double places of residence.

Traumatic Stress and Stressors

In total, of the 29 parents, 24 parents (83%) exhibited traumatic stress (either ASD or PTSD). When the infant was diagnosed in utero, eight of nine mothers (88%) and six of nine fathers (66%) developed PTSD in response to the infant's diagnosis and subsequent stressors within PICU. In this group, only four parents (one mother and three fathers) were not diagnosed with a traumatic stress disorder. Of parents whose infants were diagnosed postbirth, ASD developed in all seven mothers and three of four fathers, whereas PTSD developed in one mother and one father (a couple) whose infant stayed in PICU more than 4 weeks. In this group, only one parent, a father, was not diagnosed with a traumatic stress disorder. The difference in parental stress-related disorder between mothers and fathers was not significant (p = 0.85, Fisher exact test).

The main traumatic stressor to parents in PICU was fear that their infant could die. Fifteen mothers and nine fathers talked of being flooded with images of death. This fear was compounded by a range of stressors associated with the possibility of death. These included the appearance of their infant in response to treatment (She looked like she was dead), their infant's open chest wall after surgery (Nothing prepares you to see the open heart. I just burst into tears), the PICU environment
itsel (It was alien), hearing that their infant had a poor prognosis (They told us nearly every day that he might not make it), hearing that their infant had sustained a serious complication, being witness to another child’s death, or their fear of their own child’s imminent death. Consequently, the majority of parents were highly anxious. One parent said that he and his wife “were ready to have a heart attack themselves because of the stress,” one parent reported “twitching,” two parents talked of “shaking,” four parents said that the PICU was horrible, one parent shut out the surroundings of the PICU from his mind, two parents were angry at their infant’s appearance after surgery, and two parents said that they curled up in the fetal position when their infant was having surgery. However, in contrast, some parents reported, without emotion, serious complications, such as cardiac arrest.

**Losses**

All parents experienced loss in response to the diagnosis in the sense of losing the expectation of a normal infant. A typical response was “The diagnosis felt like everything had been ripped apart.” Secondary losses also occurred. Eight mothers felt loss due to the barriers to intimacy with their infant: “At times I just wanted to pick him up, but he had so many wires … I thought where do you hold him?” Twelve parents had to contend with their infant’s serious medical complications and five parents witnessed their infant’s cardiac arrest(s), compounding their sense of loss of a normal infant.

**Parent-Infant Relationship**

Eight of 16 mothers (50%) and five of 13 fathers (38%) reported that they had problems with bonding. Of these, three of the mothers and the five fathers said that they felt no bond at all to their infant in PICU and that “the infant belonged to the staff.”

**Adaptation**

In spite of their suffering, 10 parents (34%) revealed some adaptation to their situation. Three parents said that they began to adapt after the diagnosis at the mid-term of the pregnancy. Seven other parents began to adapt in the PICU: for example, “It is such a shock [seeing the open chest wall and the beating heart] … I nearly freaked out … and then I became accustomed to the PICU … It’s a little world of its own and you toughen up in a way while you’re there.” These parents were beginning the process of adaptation to their infant’s HLHS and to the environment of the PICU.

This process was assisted by the staff. Four parents trusted their infant to the safe hands of PICU staff. Five parents spoke about the support of the cardiologist and nine parents spoke about the surgeon’s assistance. Seven parents said that that the doctors in the PICU communicated well and humanely: “Every day we started to cope a bit better because we got enough information from the doctor.” Eight parents remarked that nurses were compassionate, communicated well, and helped them to rest. Other comments were about family and community supports, pastoral care, and church-based supports.

Some parents relied on their own resources. Four parents spoke of their spirituality: “We are Muslim and you accept these things … It is fate … and whatever life presents you need to accept it positively.” Four parents educated themselves about HLHS, and two parents said that they became assertive about their needs in the PICU. Other parents described different strategies. One parent focused on the machinery, one parent learnt parenting skills in the PICU, one parent was encouraged to see other children survive, one parent reinterpreted negative events positively, and two parents felt protected by a short stay of their infant in the PICU. The most common response was the theme of being positive. For example, one parent said that “I would look outside and the sun was shining and I would have a little bit of hope.”

**Response Differences Between Mothers and Fathers**

Although the SCID test results did not reveal any difference in traumatic stress reactions within couples, other gender differences emerged. More mothers than fathers spoke about their traumatic stress reactions. Fathers expressed their emotions less in relation to other difficulties. In general terms, fathers withdrew, whereas mothers wished to share their feelings. For example, a mother said: “My husband goes quiet and I want to talk. It was hard to connect and this resulted in some strain: “It was quite lonely and difficult on the marriage. You are lost to each other, because the child comes first.”

Mothers were more attuned to the interpersonal qualities of the doctors and their capacities for humane care and good communication, and they were more distressed when they perceived these attributes inadequate.

Fathers had challenges balancing the demands of home and hospital including other children and travel, which was particularly hard for those from rural areas. Two fathers said that their return to work was a sorrow and further separated the partners. One mother talked about its impact: “My husband had to go back to work. I was very resentful at times. There were dramas and horrible things that happened and he wasn’t there, women don’t have the opportunity to leave the PICU, collect their thoughts, and then return.” Fathers were more aware of the wider context of their lives and more aware of work-hospital pressures and of the potential impact on finances or their career.

**DISCUSSION**

This mixed methods study with interviews and psychometric testing is the first study of parents of infants with HLHS in PICU. It also expands the qualitative and secondary analyses of other studies of parents of children with HLHS.

We observed that parents of surviving infants treated surgically for HLHS exhibit multiple intense stresses in PICU consistent with other qualitative studies of parents of children with HLHS (37) (G Rempel, Parenting a child with HLHS whose infant includes the Norwood surgical approach, unpublished doctoral dissertation, University of Alberta, Edmonton, Canada, 2005) and with other illnesses (12, 28, 29, 38, 39). Furthermore, we diagnosed ASDs in 83% of parents. Of nine
mothers whose infants were diagnosed with HLHS in utero, eight mothers were test positive for PTSD in the PICU. Of seven mothers whose infants were diagnosed after birth, six had ASD and one had PTSD. In fathers whose infants were diagnosed in utero, six of nine fathers (69%) had PTSD, and in those whose infants were diagnosed after birth, two of four fathers had ASD and one had PTSD. The timing of diagnosis, whether in utero or postbirth, did not affect the prevalence of parental stress-related disorder.

Although the SCID test is retrospective and there were considerable intervals in some cases between discharge from hospital of the infant and study of parents, we are confident that parents were dealing with traumatic stress symptoms to the level of a PTSD or an ASD at that time because the narrative data and the test results supported each other. It is also unlikely that parents using retrospective recall overestimated their distress because, with the majority of their children being less than 6 years, their experiences were clear in their minds. Other studies, using different traumatic stress instruments, have verified that respondents are usually consistent in reporting traumatic stress even those that have occurred in childhood (40). Furthermore, testing with the SCID has yielded reliable diagnoses of mood and anxiety disorders with acceptable interrater agreements (0.70–0.80) (41), and the SCID test is considered a robust method of assessing traumatic stress (42). Finally, the results of the psychometric test were corroborated by the experiences of parents when interviewed.

This study has limitations: 1) all of the parents’ experiences relied on retrospective memory; 2) the sample size was small, 3) the SCID test has not been validated with this population, 4) the parents were interviewed at different intervals after discharge of their child from hospital, and 5) although semistructured interviews allow for individual variation in the types of themes that are explored, not all parents were asked the same questions which implies that some parents may have experienced problems which were not explored.

Notwithstanding these limitations, a very high prevalence of traumatic stress was identified in this study in comparison with other studies of children with serious medical conditions. Indeed, a recent study identified higher levels of stress in patients whose primary roles are parent psychological support, team meetings with parents and various professionals within the PICU, communication with mothers in the maternity hospital and fathers at home, and ongoing psychological counseling. Prebirth counseling is vital so that parents are well prepared to make decisions about the infant’s management and for the parents’ own psychological health.

Fifty percent of mothers and 39% of fathers in this study reported stress-related barriers to a normal parent-infant relationship, which is important for parent-infant bonding and ultimately for child development (37). These observations imply that the nature of the PICU itself inhibits parent-infant bonding. Stressors have previously been recognized as barriers to the formation of a normal parent-infant relationship (8) (G Rempel, Parenting a child with HLHS whose infant includes the Norwood surgical approach, unpublished doctoral dissertation, University of Alberta, Edmonton, Canada, 2005). Strategies to facilitate parent-infant bonding could include those to dealeniate and personalize PICU. Furthermore, staff should be sensitive to a parent’s need for intimacy with their infant by encouraging parents to touch and hold the infant.

Alternatively, the reporting of barriers by parents in this study could indicate an ambivalent attachment which may relate to a desire to protect themselves should their infant die. Indeed, in support of this notion, some parents reported, without emotion, serious complications in their children, such as cardiac arrest, as if this was a part of normal experience. Otherwise, this may illustrate the degree of numbing, but alternatively, it may be a feature of adaptation.

As in other studies, many parents found stressors in their relationships and communication with the staff (11, 30, 31) (G Rempel, Parenting a child with HLHS whose infant includes the Norwood surgical approach, unpublished doctoral dissertation, University of Alberta, Edmonton, Canada, 2005). This implies, as strongly recommended in other literature that staff should receive education about communication with parents (13, 23, 31) and about parents’ psychological needs. Notably, the stressors related to communication were reported only by parents whose first (or only) language was English. This may signify that they had higher expectations about good interpersonal communication, or that parents whose first language was not English may have experienced this stressor but did not comment on it or they may have felt that it was inappropriate or imprudent to comment negatively.

Some gender-specific stresses were noted which supports other studies (27, 43). Mothers bore the brunt of stresses related to care of the infant, while fathers were more affected by logistical and financial difficulties.

In spite of the parents’ experiences of stressors and losses within the PICU, some parents began the process of adaptation to their infant’s serious medical condition, in spite of the stressors they experienced including traumatic stress. Positive experiences that coexist with stressors for parents in the PICU have also been observed in other studies (27). Parents were assisted by adoption of a positive attitude and the mobilization of their own resources. They were also helped by positive engagements with the staff. Such communication assisted
parents to understand the treatment of their infant, easing their distress. Some parents were assisted by community supports (44) or by their religious affiliation (45) (G Rempel, Parenting a child with HLHS whose infant includes the Norwood surgical approach, unpublished doctoral dissertation, University of Alberta, Edmonton, Canada, 2005).

The contemporaneous psychosocial status of parents in PICU, including their resilience, requires study. In addition, the psychosocial status of parents of nonsurviving infants requires study. The latter may have profound grief experiences as a result of their child’s death or they may feel that they did the best for the child while the child was alive which has reduced their grief.

CONCLUSIONS
Parents of infants with HLHS experience many stressors and losses in PICU. The majority of parents in this study exhibited an acute distress disorder or a PTSD after the diagnosis, and their traumatic stress was compounded by their experiences in the PICU. Parents could be assisted by strategies that promote communication and understanding and the parent-infant bond. Despite negative experiences, a proportion of parents displayed resilience with some adapting to their situation.

REFERENCES
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