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International Adaptation: Psychosocial and parenting experiences of caregivers who travel to the United States to obtain acute medical care for their seriously ill child

Rachel Margolis, MSW, LICSW^{1,*}, Erica Ludi, BS², Maryland Pao, MD², and Lori Wiener, PhD, DCSW³

¹Clinical Center, Social Work Department, National Institutes of Health, Bethesda, MD

²National Institute of Mental Health, National Institutes of Health, Bethesda, MD

³Pediatric Oncology Branch, National Cancer Institute, Center for Cancer Research, National Institutes of Health, Bethesda, MD

Abstract

Despite the increasing trend of travel for medical purposes, little is known about the experience of parents and other caregivers who come to the United States specifically to obtain medical treatment for their seriously ill child. In this exploratory, descriptive qualitative study, we used a semi-structured narrative guide to conduct in-depth interviews with 22 Spanish or English-speaking caregivers about the challenges encountered and adaptation required when entering a new medical and cultural environment. Caregivers identified the language barrier and transnational parenting as challenges while reporting hospital staff and their own families as major sources of support. Using the results of the study as a guide, clinical and program implications are provided and recommendations for social work practice discussed.

Keywords

international medical travel; caregiver; pediatric; transnational parenting; psychosocial; cultural adaptation

Introduction

Caring for a child with a serious or chronic illness can be a distressing experience for a parent both in and out of the hospital setting (Christian, 2010; Hallstrom & Elander, 2007; Kratz, Uding, Trahms, Villareale, & Kieckhefer, 2009; Rivero-Vergne, Berrios, & Romero, 2008; Shields, 2001). Often parents must restructure their lives and priorities in order to manage their child's disease as well as the emotional well-being of other family members (Kratz et al., 2009). This is especially true when the child's care requires travel away from home.

In the last few decades, there has been an increasing trend in international travel for medical purposes, including families who travel to the United States (U.S.) to seek treatment for their ill children. In 2006, approximately half a million international trips took place for the purpose of medical treatment (Reed, 2008). These trips traditionally fall under two

*Please send all correspondence to: Rachel Margolis, MSW, LICSW, National Institutes of Health, 10/Clinical Center, Room 2-3581, Bethesda, MD 20892-1160, Phone: 301-402-5282, Fax: 301-480-5264, Rachel.margolis@nih.gov.

categories: international medical travel and medical tourism (Horowitz, Rosensweig, & Jones, 2007). International medical travel involves patients with financial resources traveling from developing countries to developed nations, like the U.S. or Europe, in order to obtain medical care that is unavailable in their home country (Massimo, Wiley & Caprino, 2008; Horowitz et al., 2007; van Dusen 2008). Medical tourism generally consists of patients from the U.S. or Europe traveling to developing countries in order to obtain medical treatment that is affordable and timely (Horowitz et. al, 2007; Pafford, 2009; Reed, 2008). Many uninsured patients, or patients whose insurance companies exclude preexisting conditions and elective surgeries seek this option. In both situations, patients have illnesses, injuries or conditions for which they need medical evaluation or treatment, are willing to travel to get the care they desire, and are unable or unwilling to get treatment in their home country (Horowitz et. al, 2007). In the case of acutely ill children, both categories can come into play as parents desperately search for a treatment that can save their child's life.

Traveling internationally presents a unique set of challenges for parents and caregivers. When family members leave their country of origin, children or dependents are often left behind with alternate caregivers. Reports in the anthropology and psychology literature have focused on the effect on the family when a parent or another adult family member goes to another country to seek a better opportunity for the family (Hondagneu-Sotelo & Avila, 1997). This separation has been described as extremely stressful for a family and has led to the development of a concept called transnational parenting (Falicov, 2007; Hondagneu-Sotelo & Avila, 1997). Attempting to fulfill parental roles back home while residing in another country has been associated with a myriad of mental health challenges (Falicov, 2007).

While there is significant literature that describes the stresses caregivers of children with chronic conditions experience, there is a dearth of literature on the psychosocial experience of parents and caregivers who leave their countries of origin in order to seek the best quality medical care for their child. Even less is known about their adjustment, health outcomes, resource utilization and potential psychosocial risks. In one study identified (Crom, 1995), five mothers from South America who brought their children to the U.S. for treatment were interviewed. All women were married, literate and seeking cancer treatment for their child. These mothers described the tremendous impact of the diagnosis, the decision to seek treatment abroad, and the subsequent disruption to their lives. They also reported language and cultural barriers faced while in the U.S., and the significant role that faith played in helping them cope with their time away from home.

As the number of families seeking care for their child is increasing and no other literature has addressed the potential psychosocial risks to international families, the authors designed a qualitative study to help better understand and describe the experiences of international families. We sought to obtain greater insight into how families make the decision to seek treatment in the U.S., decide which family member will leave home with the sick child, manage parenting their children transnationally and communicate about major and less acute events. We also wanted to describe the specific challenges faced in adjusting to a new social and medical culture, whether new skills are gained, and/or their own strengths recognized. The goal of the study was to describe and highlight the unique stresses of caregivers who travel to the U.S. to seek medical treatment for their seriously ill children in order to inform future psychosocial interventions.

Methods

Study Aims

The study consisted of three aims: 1) to identify the factors affecting the decision by international caregivers to seek treatment for their children in the U.S.; 2) to describe the adaptation experience of international caregivers to the medical and social culture of the U.S. including the challenges they faced and the supports they utilized; and 3) to identify and describe the positive growth experiences of international caregivers.

Subjects

International caregivers of pediatric patients (≥ 25 years of age) with complex, acute medical conditions, currently enrolled in clinical trials who traveled to the US for the purpose of seeking treatment and/or enrolling their child in a clinical trial were eligible for the study. A caregiver was defined as any individual who accompanied the ill child to the U.S. to seek treatment and was responsible for attending to the needs of that child during treatment. The child had to be receiving treatment for a medical condition including, but not limited to, oncologic and hematological diseases, conditions requiring transplant, and rare immunodeficiency or genetic conditions. Caregivers had to be from a country outside of the U.S., away from home for a minimum of 3 months, to have traveled to the U.S. only to receive medical care for their child, and be fluent in English or Spanish.

Measures

The study design team consisted of interdisciplinary professionals: a pediatric oncologist, 2 social workers, a nurse, 2 psychiatrists, 2 licensed clinical psychologists, and 2 cancer research-training fellows. The team met on a regular basis over one year during which time a thorough literature review was followed by focus groups with international caregivers whose children were undergoing treatment at the Clinical Center of the NIH. The team then developed a 12-question semi-structured interview guide in English that centered on the three aims of the study and utilized a narrative framework in order to facilitate open exploration of the phenomena of interest (Appendix 1). Prompt questions in each area were included to be utilized as needed. In order to develop the Spanish version of the interview tool, the English version was translated into Spanish for semantic and content equivalence by bilingual researchers involved in the study and then back-translated to English by NIH professional translators. The NIH Combined Neuroscience Institutional Review Board approved this study.

Procedures

The lead study investigator (LW) trained four members of the study team in interview procedures to ensure consistency and competency in the completion of the interviews. Caregivers that met the inclusion criteria were then recruited to participate. Between June of 2010 and April of 2012, a total of 23 caregivers met eligibility requirements. Using a convenience sample, eligible caregivers were identified by the child's primary medical or psychosocial team and were approached and informed about the study by one of the study investigators. All but one caregiver agreed to participate. After consent was obtained from the caregivers (in English or Spanish), the interview was conducted in English or Spanish with one of the trained, bilingual interviewers using the semi-structured interview guide. The interview ranged in length from 36 minutes to 90 minutes (mean interview time was 53 minutes). In total, 19 hours of data were collected. Participants were compensated \$25 for their time.

Data analysis

Each interview was audio recorded, transcribed verbatim, and translated, if necessary, by an independent contractor. The research team used a conventional approach to content analysis to collect, organize, and analyze the data. A conventional content analysis approach is appropriate when “existing theory or research literature on a phenomenon is limited” (Hsieh & Shannon, 2005, p.1279). This approach allows researchers to gain knowledge of a phenomenon that is based on the unique perspective of those experiencing the phenomenon and is grounded in the actual data (Hsieh & Shannon, 2005). Two Associate Investigators (AIs) utilized an open coding process to identify themes within the data (Seidel & Klaus, 1995). As part of the process of ensuring the validity of the data collected, the researchers kept a clear account of the process of classification of data that evolved into the coding structure and then into clearly defined explanations (Mays and Pope, 2000). To begin, they reviewed several of the transcripts to establish a list of codes using the initial study aims as a guide. The two AIs then independently coded half of the transcripts and organized the codes into NVivo 9.0, a qualitative software management package, for further data management. The researchers met to discuss and refine the coding scheme, as well as to integrate other interview themes that had emerged during the coding process. After refining the coding scheme, the two AIs independently coded the remaining interviews. Once they completed the coding process, the research team met to review interpretation of the qualitative results. After 22 interviews, there was consensus among the study team that saturation of data had been reached. In other words, the research team was not seeing new information or themes emerge from the data and did not expect additional interviews to yield new or valuable information. It was at this point that enrollment ended.

Results

Twenty-two parents or caregivers participated in the study. Fourteen participants spoke Spanish and 8 spoke English. The mean age of the caregivers was 39 years (range 25-53 years) and education level ranged from elementary to Master’s Level. See Table 1.

Aim 1: Decision to Seek Care

The overwhelming majority (95% or 21/22) made the decision to seek treatment in the U.S. because of a lack of treatment options in their home countries. As one mother stated, “For us it was the only option...the only open door.” Indeed, many caregivers faced limited options when it came to treatment for their child’s illness in their home country. Some participants had exhausted all standard therapies for treatment of their child’s disease at home. For other participants, treatment at home had become unaffordable, and participation in experimental therapies that had no cost associated with them allowed them a unique opportunity to gain access to needed medical care. As one father reflected, “I really wanted to come here, because the US had opened a door for me, because a treatment like that, so expensive, and they were going to give it to me for free.” Other reasons stated by participants included limited medical information at home or encouragement from physicians that the family seek treatment for the child in the U.S. One family sought treatment in the U.S. even though treatment was available in their country due to their distrust of their country’s medical system. When asked to describe how they found out about the option to seek treatment in the U.S., the majority of participants mentioned referral by home physicians or other staff at their home hospital. Other sources included discussion with former patients from their home community and information learned from the Internet.

Aim 2. Adaptation

Challenges—For all Spanish-speaking participants, the language barrier was the most prominently reported challenge. Learning how to find resources to attend to even their basic

needs, (e.g. a restroom) was described as extremely stressful when families first arrived. Not being able to communicate in their own language with the medical team in order to fully understand their child's illness and required treatment caused significant distress, even with medical interpreters available. Other challenges included limited financial resources, particularly when there were only specific, hard to find and expensive food items their child wished to eat from their home country. The emotional burden of parenting a sick child in another country was also described as a major challenge in over three quarters of the participants. Examples are included in Table 2.

Supports—Participants were asked to identify the kind of support that is important to them and what has helped them cope since coming to the U.S. Hospital staff, their own family, the church and financial donations were the most frequently reported sources of support (Table 3). Participants also emphasized the need to utilize their communal or kinship networks in order to ensure care for children left behind.

Aim 3. Positive growth experiences

Eighty-six percent (19/22) of participants reported that they experienced personal growth as a result of coming to the U.S. to seek medical treatment for their child. Table 4 illustrates the four major areas that they highlighted: shifting priorities, higher levels of self-confidence, enhanced coping skills, and greater compassion for others.

Discussion

The findings from this exploratory study illustrate the significant challenges international caregivers face in multiple realms including language barriers, financial strain, and the emotional burden of separation from home and family. Fortunately, caregivers were able to highlight sources of tangible and emotional support that helped them adapt and cope. Given the multidimensional role of the social worker on the healthcare team (Abramson & Mizrahi, 1986; Kitchen & Brook, 2005; Judd & Sheffield, 2010), social workers are uniquely poised to connect caregivers to these sources of support and to aide them in the adaptation process.

Implications for Practice

Prior to Arrival—The benefits of preadmission communication between patients and healthcare staff, in particular social workers, have been well documented (Boone, Coulton, & Keller, 1981; Berkman, Bedell, Parker, McCarthy, & Rosenbaum, 1988; Evans, Hendricks, Lawrence-Umlauf, & Bishop, 1989). We suggest that for families planning to leave their country of origin with a sick child, contact should be initiated as soon as care has been arranged at a new hospital. A phone call, preferably by a social worker, should include a preliminary psychosocial assessment. Using the key stressors identified in this study, this early assessment should include 1) the caregiver's and the child patient's literacy (ability to understand written information even if it is in their native language), 2) the caregiver's and child's fluency in English (ability to communicate with staff members and in the community), and 3) the families identified concerns (e.g. housing, special nutritional needs or requirements, ill family members at home, financial stressors). In addition, the social worker should assess the caregiver's perception of the course of the patient's illness, what the child and caregiver currently understand about the illness and treatment, and their expectations concerning the outcome of treatment in the U.S. medical setting. This first contact allows the social worker to begin the process of building rapport, can help prepare the caregiver and family for what to expect when arriving at the U.S. medical institution and can begin to dispel any myths or misunderstandings. The social worker can identify the specific resources the family will need and put these into place early. The knowledge

obtained can also be used to help prepare the medical team for the particular needs of the patient and caregiver, which in turn can facilitate an overall easier transition. Communicating information about the psychosocial and cultural background of patients and their families can assist the physician's effectiveness (Abramson & Mizrahi, 1986).

Arrival—It has been documented that part of the role of a hospital social worker is to serve as a liaison to patients and families (Abramson & Mizrahi, 1986). Hence, a structured orientation process led by the social worker may be helpful for international caregivers upon their arrival to the new medical setting. For example, caregivers can be introduced to resources within the hospital such as interpretive services, the chapel, and the cafeteria. Taking a caregiver on a tour of the hospital can further build rapport between the caregiver and the social worker, for example, to allow space for the caregiver to share pertinent information or express emotions that they may feel uncomfortable revealing in front of their child. In addition to internal resources, other helpful interventions include connecting caregivers to local community resources such as Latin or other international markets, specific religious or cultural communities, and when available, other families who share their language. It is also imperative that social workers understand what resources are not available to international caregivers and families. Depending on the type of visa, caregivers and pediatric patients who travel to the U.S. for medical treatment may not have access to public schools or government programs and resources such as Supplemental Nutrition Assistance Program (SNAP). Problems can be averted if international caregivers know these limitations ahead of time and social workers are able to identify alternative resources (when they exist).

Throughout the treatment period—Even with supports in place, traveling internationally to seek medical treatment for an ill child is likely to be a difficult experience for caregivers. Thus, the goal of the social worker should be to minimize distress by helping the caregiver navigate the new medical and cultural environment. Through the relationship between the social worker and the caregiver, the social worker can assess new psychosocial needs as they arise and address the ongoing challenge of helping caregivers cope with their child's illness while being separated from their home and family. We cannot overemphasize the potential for complex provider-caregiver interactions when addressing treatment decisions for a sick child and potential problems due to misinterpretation of medical information. If time and resources are available and the caregiver is interested, in addition to identifying skilled medical interpreters, linking caregivers with a program that teaches English as a second language (ESL) can be extremely useful. A sense of empowerment can emerge as caregivers obtain a greater sense of competency. As caregivers in this study reported the challenges associated with parenting their ill child, therapeutic services, such as individual and group counseling, should be offered to assist caregivers with the enhancement of coping skills.

This study has several limitations. First, our small convenience sample consisted of mainly Spanish and English speaking international caregivers and may not reflect all parents who seek medical treatment for their children in the U.S. Next, for 3 of the other participants who conducted the interview in English, English was not their native language. While the interviewers tried to clarify that each question was understood by an appropriate response, it is possible that misinterpretations could have occurred or more in-depth information obtained if these caregivers were speaking in their native language. Finally, another potential limitation can be the unique nature of the medical environment in which the study was conducted. While some of the children had received care at a tertiary care facility prior to arriving at NIH, the children of the caregivers in this study were all currently receiving medical treatment as part of a clinical trial. Future studies may want to include international

caregivers whose children are receiving care at a wider variety of medical facilities in order to provide more generalizable results.

Conclusion

To the best of our knowledge, aside from Crom's report of 5 Latin American caregivers (Crom, 1995), this is the first investigation to explore, describe and highlight the unique stresses of caregivers who travel to the U.S. to seek medical treatment for their seriously ill children. Several variables were identified as necessary to help international caregivers adapt, cope and ease some of their burdens. The support of the hospital staff starting prior to the arrival in the U.S. is critical for international caregivers, as is the ability to consistently connect with family members back home. Prayer and connections with faith-based individuals or programs were also identified as a particularly helpful. While the international caregivers in our study described transnational parenting to be demanding and challenging, all of the participants reported positive growth experiences including an ability to reframe their priorities in life, have greater compassion for the plight of others and feel more competent and confident in their own abilities as people and parents. We are hopeful that the resilience identified in our participants and the insight and experiences that they so generously shared will provide guidance to social workers and other healthcare practitioners as they work to develop, implement, and evaluate strategies to assist international caregivers adapt to a new medical and cultural environment and cope with caring for a seriously ill child outside of their country of origin.

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Appendix 1

Semi-structured interview guide

1. We would like to begin by hearing about how you made the decision to come to the United States for your child's medical care. I'd like you to think back to when you first found out about your child's illness - about what your doctors told you, and also your own thoughts about your child's illness. Take a minute to remember everything you can about it and please tell me as much as you remember about this time.
2. Sometimes when people find out that someone in their family is ill, they might get scared or nervous, especially if they are unfamiliar with their child's disease. Can you tell me about how you went about learning more about your child's illness?
3. Can you tell me about how you heard about the option to get treatment in the US, and how you made the final decision to come?
4. We would like to learn more about your experience once you got to the hospital in the US, for example what it was like adjusting to the hospital, its procedures, and a different health care system here. Please think back to your first weeks here when you first came here for treatment, and tell me about that experience. Try to think about the challenges and the supports that you encountered along the way.
5. We would like to learn a little bit about the kind of support that is important to you. Can

you tell us about who or what has helped you cope since your coming to the United States?
6. Sometimes when caring for a child who is ill, parents don't get to spend as much time with or have to be separated from their other children. Can you tell me about what this has been like for you as well as the other members of your family, both here and back home?
7. Every family is different in terms of how close they feel to one another and how they cope with and fix conflicts and challenges. Can you describe what your family is like, and if/how this has changed since your coming to the United States?
8. In deciding to come to the US for treatment, your family made an important decision. Sometimes people have to make an equally important and difficult decision of when to stop treatment or withdraw from a study. For example, some people might withdraw from a study or stop treatment if they felt it was not working, if they could no longer afford treatment, or because their child no longer wanted to continue. Under what circumstances, if any, would you stop coming for treatment, or withdraw from the study?
9. Sometimes care is not successful, and some parents who come to the United States for treatment have to deal with a child who does not get better. Please tell me a little bit about what a family from your community would think is the best/right thing to do if it seems like their child may pass away while in the United States.
10. Traveling to another country to seek care for an ill child can be a life-changing experience. We would like to know a little bit about if and how this experience has changed you as well as any aspects of your life.
11. What is one thing you know now that you wish you had known before coming to the US?
12. If you had to make the decision over again, would you choose to seek medical treatment in the United States?

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Table 1

Demographics

Demographic	Descriptor (N)
Home Country	Dominican Republic (7) Chile (2) Jamaica (2) Honduras (1), Guatemala (2), Greece (1), Colombia (1), Antigua (1), Peru (1), Iraq (1), Qatar (1), England (1) & Bahamas (1)
Native Language	Spanish (14) English (8)
Gender	Male (5) Female (17)
Relationship to Patient	Mother (13) Father (5) Sister (1) Aunt (2) Grandmother (1)
Caregiver Education	Elementary (3) High School (10) University (7) Master's Level (2)
Caregiver Age	Mean: 39 years (Range: 25 – 53 years)
Patient Diagnosis	Severe Aplastic Anemia (11) Acute Lymphoblastic Leukemia (2) Acute Myelogenous Leukemia (1) Lymphatic Lymphoma (1) Chronic Granulomatous Disease (1) Rare Leukemia (1) Rare Immunodeficiency (1 [*]) Neutrophil Defect (1) MENB2 Thyroid Cancer (1) Ewing Sarcoma (1)
Hospital LOS	Mean: 13.5 months (Range: 3 – 32 months); SD: 9.9 months
Patient Age:	Mean: 12 years (Range: 4 – 19 years)

* Mother and father of one patient were both interviewed.

Table 2

Challenges families face while in the U.S.

Source (N=22)	% (N)	Description	Quotes
Financial strain	91% (20)	Cost of obtaining treatment in home country	<i>"Really hard! We didn't know where to turn, and we were thinking of selling my house...to continue with the treatment...with the transfusions."</i>
		Loss of income/inability to work	<i>"Completely without work, and we left everything to come here. On top of that, since [we had to arrive in the U.S. within two or three days], we had no money to travel with."</i>
		Expense of travel to U.S. for treatment	
Language barrier (N=14)	100% of Spanish-speaking caregivers (14)	Communicating in a medical setting	<i>"The biggest challenge was the language. In the hospital, one cannot use one's own words, you have to make use of another person in order for you to say what you are feeling. This was the first challenge."</i>
		Having to rely on interpreters or one's child to communicate about important matters	
Parenting an ill-child	77% (17)	Providing consistent discipline when home supports are unavailable	<i>"It's really difficult, cuz you have a life, and when you're here, it's like you don't have a life no more; it's just you and the sick kid..."</i>
Emotional burden	77% (17)	Adjusting to a new culture	<i>"It's hard for me to deal. In my country, usually the wives [take] care of our children...the conditions don't allow for us to be like in our country. So we do it...but it's hard for me."</i>
		Being separated from home	<i>"You don't have your house, you don't have your things, you don't have your family, you don't have your country, you don't have your language, and you try to make life be as real as possible."</i>
Transnational parenting	73% (16)	Emotional affects of separation from other children	<i>"Separated? Really hard because I'd want to give my children time, too. They're small...my girl says to me, 'Mami, you love your niece more than me.' I say, 'No, mami! I love you both the same!'"</i>
		Affects of physical separation from other children	<i>"It's not just the emotional part that your children are not close. It's concern about what was happening, what they will be feeling, who they're hanging out with, so many things in the world that you don't know."</i>

Table 3**Key Supports Identified as Aiding the Adaptation Process**

Source (N=22)	% (N)	Description	Quotes
Hospital Staff	91% (20)	Nurses, primary doctors, social workers, psychiatry and other administrative staff	<i>"The support we get here is from our nurses, our doctors, our friends... I believe that has been fundamental for making our burdens lighter."</i>
Own Family	82% (18)	Talking or video-chatting with family members back home; having extended family in the United States	<i>"My family has given me lots of support... On Sundays we get together. They line up to talk with me, they call me by telephone. They spend hours talking with me, and [I talk] with each one."</i>
Church	77% (17)	Going to the chapel in the hospital; having chaplains visit; finding a church in the community	<i>"The church, because, one never stops trying to find refuge in a religion... There at the church you meet a community of friends who also help and who give you a hand."</i>
Financial	77% (17)	Fundraising in community; donations from friends; family financial support; from government	<i>"We did marathons, we did raffles, we did collections; many people gave us money. Because, we don't have money, and to come here takes a lot. But thank God we didn't lack anything."</i>
Other families	68% (15)	Meeting other families in the hospital that share the same experiences	<i>"The main source of support that will never stop being important are the families of the other patients. When you meet someone who speaks the same language... shares the same problems, shares the same space... this has really been the biggest support."</i>
Basic Needs Assistance	64% (14)	Receiving help with food and shelter from the hospital residential facility or gift cards	<i>"The Children's Inn in the hospital is very important for families. And they do very good things for children. They have facilities, they have programs, they have food. There is some other donation support. For example, restaurants, hotels."</i>
Interpreter Services (N=14)	64% (9)	Having an interpreter present or the option to use the phone	<i>"After I told them I know English, they still brought a translator which was from Iraq... and it's good that you know there's somebody who speaks your language... they really know our culture and that makes a difference."</i>

Table 4

Categories of Positive Growth for Caregivers

Category	%N	Description	Quotes
Shifting priorities	55% (12)	Changing attitude towards what is important each day Changing short term and long term goals Closer family relationships	<i>"Now I think more in at least taking one day to devote entirely to the family and be there more. Because work isn't everything."</i>
Higher levels of self-confidence	45% (10)	Recognizing one's own strengths and abilities Pride of mastery of new skills	<i>"It's satisfying that you've done what you can for your child until the very end."</i>
Enhanced coping skills	41% (9) Being able to identify and ask for help when feeling stressed	Learning to cope with chronic stress	<i>"Every day I get stronger, and stronger because back home when [my nephew] was sick back home, I'll tell you, I was very weak. But since I came here and saw others patients, it let me get stronger."</i>
Greater compassion for others	18% (4)	Acknowledging and appreciating the needs of others	<i>"Having cared for him has given me a heart more sensitive to the suffering and needs of other people."</i>