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ORIGINAL ARTICLE

The experiences of families living with the anticipatory loss of a school-age child with spinal muscular atrophy – the parents' perspectives

Bao-Huan Yang, Pei-Fan Mu and Wen-Sheng Wang

Aims and objectives. To probe into parents' anticipatory loss of school-age children with Type I or II spinal muscular atrophy.

Background. Spinal muscular atrophy is a rare disorder that causes death. Children die early due to either gradual atrophy or an infection of the lungs. Therefore, family members experience anticipatory loss, which causes grief before the actual loss. Family members feel physically and mentally exhausted, which results in a family crisis. Therefore, it is important to explore their experiences related to anticipatory loss to assist with the adjustment of the families to their circumstances.

Design. This study applied a phenomenology method and purposive sampling.

Participants. The 19 parents who participated in this study were referred to us by two medical centers in Taiwan. Their average age was 32–49 years.

Methods. Using in-depth interviews, this study explored parents' anticipatory loss. The interviews were recorded and transcribed. Meanings were extracted using Giorgi analysis, and precision was assessed according to Guba and Lincoln, which was treated as the evaluation standard.

Results. Four themes were identified from the parents' interviews. The themes included enduring the helplessness and pressure of care, suffering due to the child's rare and unknown condition, loss of hope and a reinforcement of the parent–child attachment, and avoiding the pressure of death and enriching the child's life.

Conclusions. The research findings help nurses identify anticipatory loss among parents of school-age children with type I or II spinal muscular atrophy. They enhance health professionals' understanding of the panic that occurs in the society surrounding the families, family members' dynamic relationships, and the families' demands for care.

Relevance to clinical practice. In an attempt to providing intersubjective empathy and support with family having a child with type I and II SMA, nurses may recognize relevant family reactions and enhancing their hope and parent-child attachment. Encourage family members and child go beyond the pressure of death and create customized care plans meeting families' emotional and medical needs.

What does this paper contribute to the wider global clinical community?

- The themes identified enhance understanding of the parental struggle with anticipatory loss of a child.
- The themes show that anticipatory loss affects the families' wider community.
- The findings provide insight into anticipatory loss dynamics so that nurses may provide the best possible care to help parents and families adjust to their situation.

Authors: *Bao-Huan Yang*, PhD, RN, Associate Professor, School of Nursing, Chang Gung University of Science and Technology, Guishan District, Taoyuan City; *Pei-Fan Mu*, PhD, RN, Professor, Director, Institute of Clinical Nursing, National Yang-Ming University; Taiwan Joanna Briggis Collaborating Center, National Yang-Ming University and Join Professor, School of Nursing, National Defense Medical Center, Taipei City; *Wen-Sheng Wang*, PhD, Professor, Department of Philosophy, National Chengchi University,Wenshan District Taipei City, Taiwan

Correspondence: Pei-Fan Mu, Professor, Director, Institute of Clinical Nursing, National Yang-Ming University, No. 155, Section 2, Li-Nong Street, Taipei 112, Taiwan. Telephone: +886-2-2827-5657.

E-mail: peifan@ym.edu.tw

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Introduction

Spinal muscular atrophy (SMA) is a rare disorder. It is a chromosomal recessive genetic disease that causes death, and it has an incidence slightly less than that of cystic fibrosis. The incidence is about 1/10,000 to 1/25,000. In Taiwan, every year, about 30 babies are born with SMA. Usually, children with type I SMA fall ill within six months of birth and most die from respiratory failure or pneumonia within two years. Their symptoms include weakness of the limbs and body. Children with type II SMA mostly fall ill between 6–18 months after birth. The children experience neurodegeneration, muscular atrophy, and lose the ability to move. Such individuals tend to die from lung infections at around 20–30 years of age (Ministry of Health and Welfare, Taiwan R.O.C. 2015). After being informed of a diagnosis of SMA, family members must live with the deterioration of the sick child's health. They experience anticipatory loss, which influences family interactions and functions (Al-Gamal 2013). Anticipatory loss refers to situations where family members begin to feel lost due to the approaching death of a loved one (Rolland 1994). From a subjective point of view, there is limited nursing knowledge about parents' experiences with their families living with the anticipatory loss of a child with SMA. Hence, this study applied phenomenology to demonstrate the essential structure of the parents' lived experiences of anticipatory loss. The findings help nurses provide the essential care to parents, coaching them to cope well.

Background

Some scholars suggest that anticipatory loss helps family members slowly accept impending death and become prepared for the separation, allowing them to adapt to their future life (Sutherland 2009, Gross *et al.* 2012). Based on other studies, when there is a long-term anticipatory loss, family members feel physically and mentally exhausted. They might undergo a reduction in their affection towards the child with the disease, which results in a family crisis (Tan *et al.* 2012, Al-Gamal 2013, Jenholt *et al.* 2014).

When a sick child moves toward death, all family members undergo unique experiences, reactions, and negative emotions (such as grief) related to the anticipatory loss (Rolland 1994). Lou *et al.* (2015) used phenomenology to understand family anticipatory loss among mothers of 10 children with advanced brain tumours. However, few studies have focused on the family life experience of children with SMA in relation to the anticipatory loss. In one study of children with SMA, von Gontard *et al.* (2012) investigated parental stress and found that when the sick children become severely disabled, parents feel helpless, depressed, and in crisis. As the child's impending death approaches, parents perceive a loss of resources, social support and reduced quality of life. These parents sought psychological support, family harmony, and respite care to ease their extreme stress (Arias *et al.* 2011, Ho & Straatman 2013). Exploration of the family life experiences of parents undergoing the anticipatory loss of children with SMA enables the nursing staff to recognise relevant family reactions and to create customised care plans meeting families' emotional and medical needs.

Methods

Design

This qualitative study applied Husserl phenomenology (Sokolowski 2008) and purposive sampling to explore the parents' lived experiences of anticipatory loss and the commonality of their multiple representations. Parents' experiences were intentionally and collectively narrated during in-depth interviews, demonstrating the essential structure of their understanding of the anticipatory loss experience.

Participants

Purposive sampling was conducted at two medical centers in Taiwan. Participants were parents of school-age children with type I or II SMA. The children ranged in age from 7–12 years. Nineteen parents (10 mothers, nine fathers) of the children (n = 10) joined the study.

Ethical considerations

Ethical approval was granted by National Yang-Ming University (IRB: 990023). Participants were given an information statement and provided informed, written consent to participate. The researchers had a responsibility for providing the parental safety, including (1) accepting oversight by the Institutional Review Board; (2) that confidentiality and pseudonyms were used to protect participant identities; and (3) being aware of emotional risks that might result from having participated in the study.

Data collection

The data collection involved open-ended and in-depth personal interviews in the context of phenomenology, which emphasises truth and intention to describe phenomena (Sokolowski 2008). The interview questions were: 'After the child began to attend elementary school, what was the situation? How is her/his life in comparison to the past? What are the changes?'

Phenomenological philosophy requires distillation of experiences to remove all conditions (Sokolowski 2008). Using the bracketing method (Sokolowski 2008), all conditions were eliminated, yielding experiences without properties or cultural bias to understand the original matters within the consciousness of the experience.

The researcher conducted the interviews in a convenient and comfortable place that allowed the participants to express themselves freely. A total of 19 parents participated in the research. Seventeen participants were interviewed at home, whereas two participants were interviewed in a quiet part of a restaurant. This study was conducted from March 2010–March 2012.

The data were gathered from parents' collective perceptions (Mu 2008). Nineteen parents participated in interviews relating to 10 children. In one of the 10 families, the parents had divorced, and only the mother was interviewed.

Each interview took about 1·5–2 hours. Before each interview, the researcher guaranteed the complete confidentiality of the personal information collected via an audio recording and received the participants' agreement for recording the interview. In addition, the researcher record the participants' relevant language and nonlinguistic behaviours. The participant's flow of consciousness revealed a view of their life experiences. This approach allowed the parents to express their experiences and feelings about the care of their sick child freely. When the meanings of the items or details were not clear, the researcher asked for clarification. In the interviews, the researcher encouraged conversation between the participants and tried to avoid dominance by one parent. When the participants' opinions were contradictory, they were asked to clarify their points. Finally, the researcher determined if the participants had any further opinions. Fifteen participants were interviewed twice, and four were interviewed once. After collecting the data from the last set of parents, and based on an analysis of its completeness, the researcher confirmed the integrity of the data and stopped the collection.

Data analysis

Data analysis was based on the Giorgi phenomenological method (Giorgi 2008) using transcriptions of the interviews together with the supporting journal of nonlinguistic behaviours of each parent. There were three steps in the analysis: (1) reading the data to obtain its completeness, (2) determining the units of data, recognising meanings by analysing the data, and repeating the data reading until the researcher's language fully expressed the unit, and (3) combining the data using imaginative variation to identify the essential structures of the experience. The researcher translated the essential structure of the participants' life experiences into sensitive and expressive phenomenological terms that allowed communication with academic groups (Giorgi 2008). The researcher read the transcripts several times as open-mindedly as possible to grasp the holistic meaning of the data. The researcher also discussed the data with the research team and peers in related fields to develop new perspectives that supplemented the researcher's insights. After coding the data, the researcher grouped similar properties together to develop subthemes. Based on the research questions, the subthemes were reorganised to form the themes. In discussions with the research team, the researcher modified the themes and studied them using the participants' language. During the data analysis, the researcher reviewed the available literature on the themes to enhance their sensibilities and adjust their viewpoint relative to the interview data. In addition, we used the approach of Guba and Lincoln (2005) to enhance the rigour of the data. This approach included: (1) persistent observation, peer debriefing, and referential adequacy for establishing credibility; (2) a detailed description of the phenomenon for establishing transferability; (3) an inquiry audit for establishing dependability; and (4) a reflection diary for increasing confirmability.

Table 1 Characteristics of children with spinal muscular atrophy ($N = 10$)

Characteristics	*n*	Mean (SD)	Range
Sex			
Male	7		
Female	3		
Age, years			
9	2	10·9 (1·29)	9–12
10	2		
11	1		
12	5		
Age at onset			
4 months	1		
8–9 months	2		
1–3 years	7		
Ranking			
Eldest child	6		
Second child	3		
Single child	1		

Table 2 Parental characteristics of children with spinal muscular atrophy ($N = 10$)

Characteristics	*n*	Mean (SD)	Range
Mother	10		
Age, years		37·7 (5·25) y/o	32–45 y/o
30–35	5		
36–40	1		
41–45	4		
Education			
Senior high/vocational school	7		
College/university	3		
Occupation			
Work	4		
No work	6		
Religion			
Taoism	4		
Buddhism	4		
Christianity	2		
Marital status			
Married	9		
Separated	1		
Father	9		
Age, years		41·9 (4·43)	37–49
36–40	4		
41–45	3		
46–50	2		
Education			
Less than junior high school	3		
Senior high/vocational school	2		
College/university	4		
Occupation			
Industry	6		
Commerce	1		
Government worker	2		
Religion			
Taoism	8		
Buddhism	1		
Christianity			
Marital status			
Married	9		
Separated			

Results

The 10 children with SMA consisted of seven boys and three girls. These children began to fall ill at ages that ranged from four months to three years. Table 1 provides the characteristics of the children with SMA. Table 2 shows the demographic characteristics of the parents. The parents ranged in age from 32–49 years. More than half of the families were Taoist. Table 3 depicts the features of the families of the children.

Based on the parents' perspectives, the life experiences of the families' anticipatory loss led to the development of four themes: (1) enduring the helplessness and pressure of care, (2) suffering due to the child's rare and unknown condition, (3) loss of hope and reinforcement of the parent–child attachment, and (4) avoiding the pressure of death and enriching the child's life (Table 4).

Enduring the helplessness and pressure of care

The families expected their children to grow up with a bright future. However, they encountered the dilemma of SMA where the experience of growing up means an early death. The parents realised that the children would never experience youth and middle age. They would not have a future, and this caused long-term grief and loss. The parents reported that children felt helpless and afraid of death. In seemingly harmonious families, the members endured stress, strong negative emotions, and conflict. Two subthemes emerged from this topic: 'family grief at losing a child' and 'family conflict due to the pressure of care.'

Table 3 Family characteristics of children with spinal muscular atrophy ($N = 10$)

Characteristics	*n*
Family style	
Nuclear family	8
Extended family	1
Single-parent family	1
Economic conditions	
Low-income	3
Economic middle-class	7

Table 4 Structure of the life experiences of the families' anticipatory loss based on the parents' perspectives

Theme	Subtheme	Category
Enduring the helplessness and pressure of care	Family grief at losing their child	An unavoidably limited life
		Children living with the fear of death
	Family conflict due to the pressure of care	
Suffering due to the child's rare and unknown condition		
Loss of hope and a reinforcement of the parent–child attachment	Seizing the opportunities for treatment and extending life	
	Ceasing ineffective treatments and strengthening family togetherness	
Avoiding the pressure of death and enriching the child's life	Facing the unknown with spiritual support	
	Share decision-making with the children	
	Making a colourful life with an inactive body	
	Preparing the child for farewell	

Family grief at losing their child

The parents were sympathetic to their child's physical decline. They realised that SMA was robbing their children's lives, and the families were under the pressure of impending death. Some parents tried to disengage from their negative thoughts by focusing on the various aspects of daily care. Many parents became depressed and anxious that they might lose their children at any moment; they sought medication to relieve their stress. Two categories contributed to family grief: 'an unavoidably limited life' and 'children living with the fear of death.'

An unavoidably limited life. The parents acknowledged that their children's lives were fragile. They wanted to avoid their children's death. They wanted them to go to school like other children. This strategy was not necessarily effective. The parents often felt depressed and helpless because their children's futures were uncertain:

I's father: 'I try to let him accomplish things. We cannot give up on him even though he has no future.'

I's mother: 'He (the sick child) said, "Oh. . .never! I do not want to do the exercise!" "We did not tell him about the future. . .since he might resist it."'

Children living with the fear of death. Parents agonised about their children's fear of death. The children were sensitive to discussions related to their disease and death. They showed anxiety about their age and lived cautiously:

H's parents: 'The doctor told her that she would only live until she was 13 years old. She thought about it when she went into grade two and again in grade three. Once she realised the effect of aging, she was afraid. She asked why she should only live to the age of 13. She even counted the years. "I am fine, Mom, I am only eight years old." I feel sorry for her. . .a little girl, worrying about her life span.'

Family conflict due to the pressure of care

Parents reported that their children with SMA were not favoured by their grandparents, which caused conflict between the generations. The parents thought that grandparents felt shame about their grandchildren with SMA and were unable to love them. Thus, the sick children encountered problems with self-identification and family support. In addition, conflicts between parents and children often erupted:

C's father: 'For a time, I was very helpless! I did not know what to do!'

C's mother: 'I felt angry! My father-in-law thought SMA was my fault! My husband did not blame his father, which hurt me deeply! I defended myself. I found that grandfather felt ashamed about his grandson! I felt stress, and I did not know why my child suffered from this. Certainly there was no answer! The emotions were reflected in our faces, and I blamed my husband. I cried in secret.'

Suffering due to the child's rare and unknown condition

When the children fell ill with SMA, doctors were unable to stop the progression of this rare genetic disease. Parents felt medical treatments were based on trial and error, not on tried and true protocols. In addition, doctors did not seem to follow-up with the patients. The parents understood that the disease was incurable, and they felt helpless. They were unable to prevent sudden life-threatening deteriorations in their children's health. They believed that intensive care doctors were ill-equipped to deal with declines in their children's respiratory organs. Parents realised that family members had more experience taking care of their child than any of the doctors they consulted. Parents complained that the health care system did not recognise their children's conditions. The parents had to handle the demise

and death of their child alone, and they felt very sad, frustrated and depressed:

E's father: 'I told the doctor that my child had respiratory problems, and it was urgent. My child was pale. The doctor only gave me a prescription. I asked him if an X-ray examination was necessary. He wanted us to go home. We dared not go. I was afraid that there would be an emergency on the way home.'

E's mother: 'We waited for another doctor.'

E's father: 'After listening to the situation, he sent our child to the intensive care unit. I told the doctor in charge that the previous doctor did not understand the disease and had delayed treatment. My child was saved this time, but if this had not happened, what would we have done?'

Parents sought emergency help at the hospital, telling doctors that their children had life-threatening breathing problems. The parents believed the intensive care experience was unacceptable. The doctors and parents had different opinions about their children's physical status. The doctors insisted on performing tracheostomies. Parents felt that their children suffered due their medical treatments:

B's mother: 'He coughed and panted after leaving the intensive care unit. The oxygen concentration in his blood was extremely low.'

B's father: 'It was phlegm.'

B's mother: 'They wanted to perform a tracheostomy. I refused and insisted on taking my child home. We wanted change to Chinese medicine.'

Loss of hope and a reinforcement of the parent–child attachment

Even though parents understood that SMA was incurable, they never gave up on their children. They tried different treatments to extend their children's lives. Unfortunately, the families frequently experienced failure. Thus, to help ease the anguish parents felt for their children, they seized the opportunity to enhance their love for their children, which helped to compensate for their children's future loss. This concept included two subthemes: 'seizing the opportunities for treatment and extending life' and 'ceasing ineffective treatments and strengthening family togetherness.'

Seizing the opportunities for treatment and extending life

The parents tried experimental and/or alternative treatments such as acupuncture in the hopes of finding a 'miracle.' Although the parents felt sorry that their child was treated like a laboratory guinea pig, they still seized these opportunities:

B's father: 'People told me that there was a doctor in Hong Kong. . .I found the doctor and talked to him. I took some Chinese medicine and covered the soles of my child's feet.'

B's mother: 'The medicine burned his feet, and it was similar to acupuncture. It was horrible.'

J's parents: 'Yes, their treatment was experimental. Currently, we cannot find a better one. At the beginning, we even gave him hydrocortisone as suggested by the doctor. My idea was that the medicine was an opportunity for the child. The principle of Depakine treatment is to supplement the deleted section in the genes of the fifth pair of chromosomes. It was necessary to treat him in this way.'

Ceasing ineffective treatments and strengthening family togetherness

Medical treatments failed frequently, and the children became mentally and physically tired. Eventually, parents gave up chasing ineffective treatments and decided to reinforce the parent–child relationship by cherishing time together:

G's father: 'We need to spend time with our child and make him happy. . .time is so important, and we should not wait.'

G's mother: 'Money or a house does not always belong to us! We should treat ourselves well. The whole family should live happily!'

Avoiding the pressure of death and enriching the child's life

Parents struggled about the inability to control their children's SMA symptoms. Even the children recognised their physical decline. They were afraid they might die during treatment or when separated from their parents. Thus, family members sought spiritual and religious support to enrich their children's lives. The parents also encouraged their children to participate in treatment decisions, giving them an active role in their care. This topic included four subthemes: 'facing the unknown with spiritual support,' 'sharing decision-making with the child,' 'making a colourful life with an inactive body,' and 'preparing the child for farewell.'

Facing the unknown with spiritual support

The parents felt frustrated and helpless as they tried to save their child. They sought refuge in religion and spiritual practices, which helped liberate and comfort them as they accepted their situation. Parents transformed their grief over the prospect of losing their child to living life to the

fullest with their child. Spiritual practices helped the families marshal the strength to cope with the unknown:

D's mother: 'One day, when Buddha takes our child away, she will have finished her practice in this life. Because of my child, I made the right decision to follow Tzu Chi. I know how to deal with the separation. When she leaves me one day, I will certainly be sad. Without religion, I would never know how to deal with her approaching death.'

Sharing decision-making with the child

The parents considered the various risks associated with a range of treatments to extend their children's lives. They explained the advantages and disadvantages of treatments to their children and asked their children's opinions. They expected their children to participate in treatment decision-making out of respect for their right to autonomy. The parents and children undertook the risks together to avoid making mistakes:

A's mother: 'Hospital K suggested spine management. I asked my child, and he refused. According to the statistics, spine management can extend the lifespan by about five years. I asked the doctor about this possibility, and he said no. The operation is extremely risky. In Taiwan, no one dares perform this treatment on these children. In addition, even after the normal operation, the pain is significant. How long will my child suffer? I would feel regret if I made the wrong decision, but I might feel better because my child participated in the decision.'

Making a colourful life with an inactive body

The parents understood that these children were normal children and had happy and pure souls. However, they were trapped in inactive bodies. The parents loved their children and wanted to liberate them and grant them a colourful life. They won opportunities to expand their children's education. They communicated with schools and constructed friendlier environments that allowed their child to be accepted by their peers and teachers. Parents encouraged their child to grow, learn, and develop strategies to boost their self-esteem and confidence:

F's mother: He used to depend on Mom and Dad when staying at home and asked us to feed him. I wanted to feed him when he came back from school. He refused. He is used to eating by himself at school. . .. Let him study, because I think every child must study- . . ..My son is so clever. Except for his inability to walk, he is different from others. . .. Actually! F really grew up!

F Dad: My idea is the same.

Preparing the child for farewell

As SMA progressed, the children were hospitalised and required mechanical respiration assistance repeatedly. The children feared separation from their parents. The parents talked to their children about their conditions to prepare them for the impending crisis and be happy enjoying their life as best they could. Parents believed it was better for the children to accept death rather than to continue guessing about it. Parents wanted to grasp the remaining time, grant their children's wishes and be prepared for the future separation:

A's mother: 'He is strong, and he can endure these things. He knows the situation completely since I explained it all to him. I told him that he might not live long and that he should seize the time available to fulfil his dreams. When he feels uncomfortable, he should let me know right away. Blockage by phlegm might kill him. He learned all these things calmly.'

A's father: 'We should tell him the truth.'

Discussion

With intentional retrospection and consciousness of internal time, the parents understood that SMA was a constant and significant threat to their child, which culminated in anticipatory loss. The parents experienced disappointments and fulfilled empty intentions when caring for their children, causing instability and conflict within their families. The perceived shortage and lack of quality professional medical care led to taking risks associated with experimental medicines and alternative therapies. This behaviour is evidence that the parents expected to extend the lives of their children. The treatments failed frequently, and the sameness of these multiple experiences demonstrated to the parents that their child would indeed die. The parents began to reconsider the meaning of family life and started enhancing their parent–child relationships. They also began to respect the child's right to autonomy and allowed the child to take on some of the risks of treatment.

The parents worried about their children's life crises. Rolland (1994) suggested that when sick children begin to deteriorate, family members tend to suffer from anticipatory loss. At this stage, the family members are highly uncertain, and they realise that their children's condition is out of their control. They suffered anxiety about their children's approaching deaths.

The parents felt constant helplessness, and this was a cause of family conflict. Rolland (1994) and Kocova *et al.* (2014) reported that when there is an anticipatory loss, family members need to escape from the site of care during

the last phase of the disease course. They become angry and frustrated with the patient. While SMA is incurable, with quality parental care the children's life spans could be prolonged. Nevertheless, each child's condition continued to decline year by year. Many parents reported that they felt tired and helpless when taking care of their children, and this was a cause of great conflict. Rushton (2012) studied Duchenne Muscular Dystrophy and SMA Type 1. He reported that families encountering the possible death of their sick children became frightened, angry and sad. According to several studies, a child's continuous discomfort increases the likelihood that parents will suffer from depression, have difficulties in life and have conflict with their children (Clinch & Eccleston 2009, Kars *et al.* 2011). Based on related research regarding childhood death, family members and/or caregivers should discuss impending death with the patient to determine their thoughts (Badger *et al.* 2012, Goodman *et al.* 2013). This study demonstrates that most parents encouraged their children to live their lives as usual and then helped them to accomplish their wishes.

Since SMA is a genetic disease, families may experience conflict between family generations. Chinese culture embraces the concept of destiny, and some parents believe that when their children have a rare disorder, the children are not favoured by their grandparents. One reason for this might be that the grandparents do not have appropriate knowledge related to caring for the child. As a result, they are unable to interact with their grandchildren during SMA care. Thus, any relationship between the grandparents and the children is unlikely to be close. These families might have misunderstanding between the generations. Bruns and Foerster (2011) suggested that mothers of children with a rare trisomy are likely to have conflict with the children's grandparents. However, any assistance from the grandparents lowers the burden of the mothers. Therefore, when a family has a child with a complicated disease like SMA, support by the grandparents is critical to enhancing family harmony.

The children with SMA and their parents experienced a lack of professional care and a dearth of useful care suggestions. Some families suggested that the physicians judged their child's situation based on standard objective symptoms and that they neglected to take into account the characteristics of the illness and the parents' care experience. The doctors tended to either overestimate or underestimate the children's conditions. In this study, some parents indicated that they expected healthcare professionals to respect their family care experience and that any provision of medical treatment should support this expectation.

In this study of anticipatory loss, parents developed significant goals for their family life. They initially tried hard to find appropriate medical treatments or alternative therapies. However, when there was no hope, most of them began to refocus on family life. They enhanced the love between parents and children and tried to make sure that their children had a good quality of life. According to related research, when the family members' efforts could not heal the patient, the family suffered from sadness, anger and frustration. They gave up treatment and tried to increase the love they had for each other (Kars *et al.* 2011, Ussher *et al.* 2011). They wanted to avoid the long-term influence that despair might have on their emotions (Kars *et al.* 2011, Ussher *et al.* 2011). Our findings demonstrated that some parents, as they began to give up on treatment, expected their child to participate in care decisions based on respect for their child's right to live autonomously. Furthermore, Mu (2011) indicated that when families allowed their children to interact with the disease and to develop their self-consciousness, they were able to appreciate the situational significance of the anticipatory loss. In this study, the parents suggested that such decision-making with the child aimed to define life values and experiences to establish family life goals with respect to the anticipatory loss. Thus, the parents suggested that by using this approach they would avoid the long-term influence of death on their family members' emotions. The families would be able to create friendly environments and enhance the significance of their sick children's lives. Some parents told their children to seize the moment and helped the children accomplish their wishes. They hoped that their children would enjoy growing up like normal children. Some parents suggested that a family is like a boat that carries and takes care of the children's last dreams, allowing them to express themselves freely and to enjoy their memories.

Conclusions

This study showed that the parents of children with SMA experienced anticipatory loss and that many facets of care impacted their sick children's lives and self-identification related to SMA. The families endured internal conflicts centered on the constant stress of caring for critically ill children. In addition, families faced generational and cultural conflicts. While they perceived shortages of professional medical care resources, the families demonstrated innovative skills to recover from many setbacks. They enhanced the love between parents and the children, respected the sick children's right to autonomy in relation to the disease, helped the children become prepared for separation and enhanced their children's lives.

The study findings serve as a reference for nursing personnel who deal with family-centered care of children with SMA. Thus, nurses help such families by empowering the family and strengthening their ability to cope well and live admirably with their impending losses.

Research limitations

The study is limited to this particular group and might not be generalisable to other locations and subjects. This study is from the parental perspective to understand the experiences of families living with the anticipatory loss of children with SMA in Taiwan. Future studies will be conducted from the viewpoint of children with SMA and their siblings.

Relevance to clinical practice

When a child has SMA, healthcare professionals should recognise the changes that the disease produces and counsel family members in advance about what to expect in the future. It is important to evaluate the child's physical functioning and to determine the physiological and pathological means of treating the child, and then communicate that information to the family to alleviate the family's uncertainty. Constructing a detailed care plan with assistive technologies and services helps parents by relieving some of the burdens of medical care. Through the use of assistive technology and services, the parents could enhance the sick child's independence and self-esteem. If the parents are confused about aspects of the child's care, this can cause family grief and conflict. In such circumstances, the nursing staff members should encourage family members to communicate with each other to avoid misunderstandings. Moreover, nurses should help families with a child undergoing long-term care to understand and to utilise respite care so that the family members may reduce their stress.

When the child is afraid of death, nurses should help family caregivers know how to respond to the child's fears. When families accept the fact of the child's inevitable death, the families' grief should be acknowledged, and information related to the process of palliative care should be provided. The nursing staff members need to walk the line between hope and the acceptance of death, while at the same time caring for the family who is facing the anticipatory loss of a child with advanced SMA.

Continuing education that targets discussing death with children, spiritual care by the clinical care team and outside resources and grief counselling, will help promote family communication to enrich the children's lives. Understanding the resilience and personal experiences of such families facing the loss of a child with SMA enables the nursing staff members to create holistic care plans for the children and their families.

Contributions

Study design: BY, PM, WW; Data collection and analysis: BY, PM; Manuscript preparation: BY, PM, WW.

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