



Caring for a Child With an Acquired Disability Unveiling Light From Darkness

Brad Phillips, PhD, RN

This study explored how parents of children with acquired disabilities transform loss into meaning when faced with traumatic experiences. This type of loss is ambiguous and different from that of the bereaved. Directed content analysis was guided by the predetermined categories of unveiling, darkness, and light. Stories from 8 parents revealed the ability to decide how they perceived their experiences, discovering meaning in caring for their child despite the suffering associated with loss. These findings offer direction for nursing research, practice, and policy on how to assist parents in overcoming these challenges and shed light on the dynamic perspectives of loss. **Key words:** *acquired disability, ambiguous loss, children, directed content analysis, grief, narrative storytelling, parents, suffering, Theory of Meaning, transformation*

BACKGROUND AND SIGNIFICANCE

In 2021, it was estimated that nearly 3.4 million children (6.7%) in the United States have a disability.¹ Various contributing factors are associated with childhood disabilities, with unexpected illness and injury among the highest causes of those acquired after birth.² An acquired disability is a permanent impairment of function following normative childhood development.³ Children with ac-

quired disabilities often require long-term rehabilitation, increased caregiving demands, and costly complex medical care.⁴⁻⁸ Because of limited supportive resources, parents often serve as primary caregivers in the home. They often experience negative effects in their overall physical, emotional, psychological, and spiritual health.⁹ This is further complicated by the ambiguous/nonfinite loss associated with the acquired disability.

Ambiguous loss is different from traditional loss in that the child is still alive, yet there is the absence of the previously healthy child.¹⁰ Nonfinite loss is expressed as a living loss that is ongoing with an unforeseen end and is often used to describe children with acquired disabilities.^{11,12} These terms are used interchangeably in the literature and conceptually describe this particular type of loss. Parents describe their experiences of ambiguous/nonfinite loss as traumatic, ongoing, recurring, and unresolved.^{12,13} Parents are anxious and apprehensive toward the uncertainty of their experiences, and there is a sense of disappointment for the changes they have experienced with their child.^{10,14,15}

Loss is commonly studied under traditional, linear, time-bound models such as

Author Affiliation: West Virginia University School of Nursing, Morgantown.

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Correspondence: Brad Phillips, PhD, RN, West Virginia University School of Nursing, 64 Medical Center Dr, Morgantown, WV 26506 (brad.phillips@bsc.wvu.edu).

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Statements of Significance

What is known or assumed to be true about this topic?

- Parents of children with acquired disabilities often serve as primary caregivers in the home. This experience has a profound impact on their overall health.
- In addition, they are suffering from the loss experienced with a change in their previously healthy child.
- Ambiguous/nonfinite loss is different from traditional loss.
- Navigating this type of loss is dynamic and fluid and poses unforeseen challenges.

What this article adds:

- In this study, parents expressed the ability to transform their ambiguous loss into purpose.
- Through active decision-making, parents were able to reframe how they perceived their role and unveil new perspectives despite the loss they experienced.
- This transformation of loss is novel in that it challenges traditional views of grief by highlighting choices parents make to discover renewed meaning within their caregiving role and experiences with their child.
- “Unveiling light in the midst of darkness” as the definition of the concept of *transforming loss* was supported by the findings of this study.

moving from denial toward acceptance.¹⁶⁻¹⁸ However, Bruce and Schultz¹⁹ suggest that there is no formula to describe ambiguous/nonfinite loss, with evidence that supports a fluid and dynamic process rather than a linear, staged model.¹⁹ Parents undergoing this type of loss have been observed by the author in settings such as the pediatric intensive care unit (PICU) and outpatient

clinics to actively work to transform their experience into a different perspective that provides meaning and purpose to them. This practice observation led to the development of the concept *transforming loss*.²⁰ Transforming loss describes the process of discovering purpose and meaning for parents experiencing an ambiguous/nonfinite loss with their child. The conceptual definition of transforming loss is “unveiling light in the midst of darkness.”^{20(p2)} It has been designed for use in nursing research and describes how parents find meaning and purpose despite the experiences associated with an ambiguous/nonfinite loss.²⁰

PURPOSE

The purpose of this study was 2-fold: (1) gather empirical evidence about the concept transforming loss; and (2) use the evidence to offer guidance for nurses on how to assist families navigating these life experiences. The question, “How do parents describe living through the experience of caring for a child with an acquired disability?” directed the research.

THEORETICAL FRAMEWORK AND APPROACH

The middle-range Theory of Meaning²¹ guided the development of transforming loss and was congruent with the study purpose. The theory is based on the premise that “meaning is a journey toward life purpose with the freedom to choose one’s path in spite of inevitable suffering.”^{21(p89)} The theory has 4 assumptions: (1) a person’s search for meaning is the primary purpose for life, and each person has a unique ability to find individual meaning without assistance from others; (2) a person has freedom to realize meaning of life and reason for existence; (3) a person can find meaning in life despite inevitable suffering or in situations that cannot be changed; and (4) a person’s life has meaning at all times, in every situation.²¹

The 3 organizing concepts within the Theory of Meaning are life purpose, freedom to choose, and human suffering.²¹ Life purpose is the reason for a person's existence. Purpose can be found through individual works, meaningful experiences, or attitudes. Purpose can also be lost or threatened from a situation that strips away meaning, such as experiencing an ambiguous/nonfinite loss. Freedom to choose is the process of having control over options. It is the ability to choose an attitude despite the situation. Human suffering is described as a "subjective, all-consuming human experience."²¹(p89) Suffering is part of the human health experience. Although meaning cannot be found within human suffering, it can be found despite it. The concepts of the theory correspond with the core qualities of transforming loss: unveiling, darkness, and light. Unveiling light in the midst of darkness²⁰ describes the transformative experience of freely choosing meaning despite the suffering experienced from an ambiguous/nonfinite loss, such as caring for a child with an acquired disability.

Story Theory structured the approach of data gathering by exploring recollected experiences associated with present, past, and future. The 3 concepts of Story Theory are intentional dialogue, connecting with self in relation, and creating ease.²² Intentional dialogue was facilitated by the author being fully intentional and present during each parent interaction. Connecting with self in relation transpired as parents began to reflect on their experiences with caregiving and loss in the context of having a child with an acquired disability. Finally, creating ease was manifested through enhanced clarity and comfort as parents began to recollect on the present and past and think toward the future.

METHOD

This qualitative, descriptive study was guided by directed content analysis.²³ When there is existing theory and research about an area of study that would benefit from further

description, a directed approach to content analysis is appropriate (Figure). There is little known about how parents transform loss into purpose and meaning when caring for a child with an acquired disability. With this method, data were collected through scripted interviews using open-ended questions, followed by targeted questions about the predetermined categories. The predetermined categories were derived from the core qualities of transforming loss: unveiling, darkness, and light.²⁰

Protection of human subjects

This study was approved by the institutional review board and academic medical center associated with West Virginia University. Confidentiality was maintained by securing data on a password-protected computer and in a locked file. Interviews, which were recorded, were conducted in a private location. Participants were made aware of the benefits and risks associated with the study, signed an informed consent, and were able to stop or withdraw from the interview at any time. Findings are reported anonymously to further maintain participant privacy.

Sample

Participants were recruited from social media support groups and word of mouth. Examples of support groups included parents of children with traumatic brain injury or cerebral palsy, parents of children with special health care needs, or Medicaid/state-based financial resource groups. To be included in the study, participants were required to be 18 years or older and a parent or primary caregiver of a child (younger than 18 years) with an acquired disability. Excluded were parents of children with a congenital disability or parents unable to independently participate in the interview process. A parent or primary caregiver was defined as someone who provided care to the child before and after the disability was acquired. The disability must have been acquired at least 1 year prior

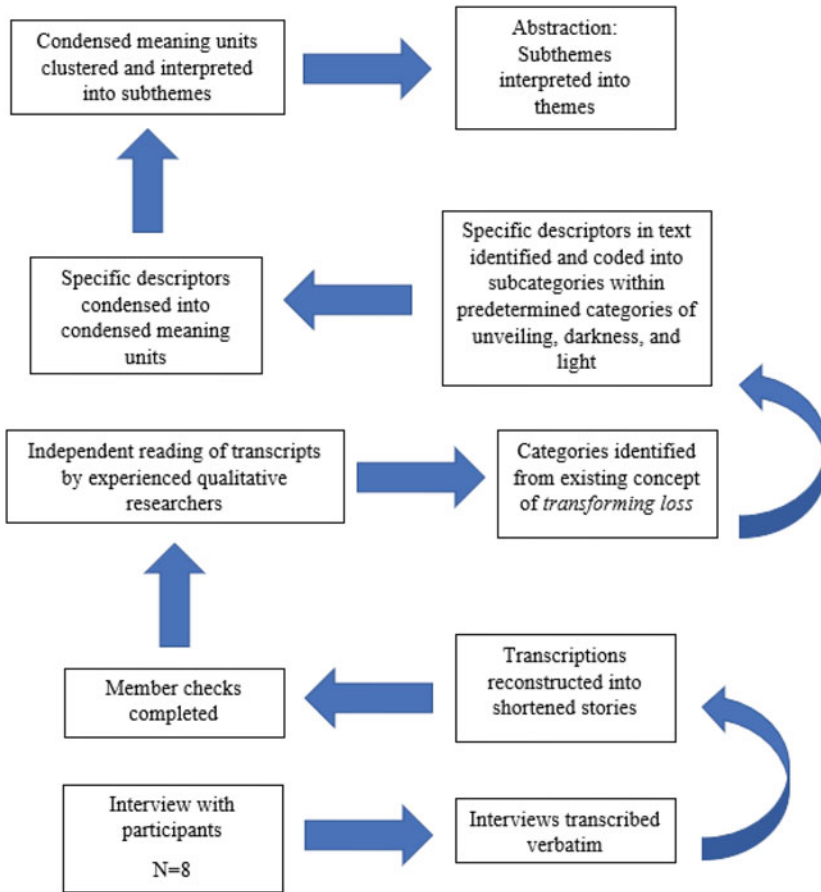


Figure. Directed content analysis model. This figure is available in color online (www.advancesinnursing-science.com).

to the interview to give the parent or primary caregiver time to grapple with the ambiguous/nonfinite loss. It is not well described in the literature what is the optimal time frame when parents begin to transcend ambiguous/nonfinite loss. One study reported that the initial traumatic grief response in parents of children with a traumatic brain injury may last from 12 to 18 months.¹¹ Another study found that key transitional support needs for parents reside in their ability to navigate the health care structure, community of support, and school system.¹⁴ Since there is not clarity on this issue, 1 year since the disability was selected as providing enough time for reflection but still close enough to the experience for accurate memories.

Interviews

The investigator used the 3 stages of Story Theory²² and the predetermined categories of unveiling, darkness, and light to create the semistructured interview questions in the order of present, past, and future. The premise of Story Theory²² is that the challenges that complicate everyday life can be better understood through a narrative. The gathered story focuses on understanding the health-related lived experience in the words of the participants with the intended outcome aimed at moving these challenges toward a resolution.²² The predetermined category of unveiling was structured to be consistent with the present caregiving experience, while darkness and light aimed to

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gather stories related to the past and future, respectively.

Procedures

Flyers were distributed to staff in local pediatric clinics and virtually via Facebook. The investigator contacted the administrative member of each support group via private Facebook message, describing the purpose of the study and asking for permission to join and post within the group. Administrative members were welcoming and receptive, giving permission to share information with group members. The flyers included a brief overview of the study, eligibility criteria, and contact information of the investigator. Despite recruitment efforts in the clinics, all participants were recruited via Facebook support groups or word of mouth. Once qualified for participation, caregivers were given the choice of an in-person or computer-based Zoom interview at a mutually agreed upon date and time.

Thirty potential participants contacted the investigator over the course of the 6-month recruitment period, but many were ineligible due to disability type. These included congenital disabilities such as cerebral palsy, spina bifida, and cystic fibrosis. Ultimately, 8 participants were interviewed: 5 in their home, 1 at the School of Nursing, and 2 via Zoom.

Prior to the interview, participants completed a demographic questionnaire, which included age, sex, race/ethnicity, county location of their home, marital status, employment status, household income, relation to child, and total number of children in the home. Child demographic data included age, sex, functional status, type of illness/injury, time since injury, and type of health care needs. Interviews were recorded and lasted between 32 and 84 minutes ($M = 52.5$ minutes). Each participant was offered a \$50 gift card as a modest thank you for their time.

The recorded interviews were transcribed by the author and then they were reconstructed into a shortened story. The reconstructed story placed the interview into the order of past (darkness), present (un-

veiling), and future (light) using the words of the participants. Once the stories were reconstructed, the investigator provided the reconstructed story to each participant via email. The investigator scheduled a second interaction with each participant so they could review their reconstructed story for accuracy and confirm or modify it. They also had the option to remove the story from the study, but none did. Following confirmation, participants received an additional \$25 gift card.

Analysis

The investigator and a second researcher with qualitative research expertise analyzed the data. The process began with the predetermined category of unveiling, where the investigator read through all 8 transcripts using a line-by-line technique and highlighted sentences that met the definition of the category. These would become the specific descriptors such as “words, sentences or paragraphs containing aspects related to each other through their content and context.”^{24(p106)} The text was reviewed, and subcategories were developed that described a broad, overarching meaning of each specific descriptor. Subcategories continued to be developed until each specific descriptor could be logically placed or clustered. The process was then repeated for the predetermined categories of darkness and light. Once all of the subcategories with specific descriptors were identified, the investigator reorganized, combined, or removed subcategories that shared similar content and context.

Once the subcategories and corresponding specific descriptors were organized, the investigator went through each subcategory and shortened each specific descriptor into a condensed meaning unit through the process of condensation, or “shortening while still preserving the core.”^{24(p106)} The condensed meaning units within each subcategory were then aggregated into clusters based on manifest and latent content. Manifest content includes the visible, obvious components of the text, while latent content involves an

interpretation of the underlying meaning of the text.²⁴

A review was completed on each cluster of condensed meaning units, and through the process of abstraction, or interpretation on a higher logical level, subthemes were created. The final process of analysis was to interpret the subthemes into themes. Themes are “threads of underlying meaning through, condensed meaning units, codes or categories, on an interpretive level.”^{24(p107)} An excerpt from the analysis audit trail can be found in Table 1.

Trustworthiness

Trustworthiness was maintained through credibility, transferability, dependability, and confirmability.²⁵ Participation in the study was completely voluntary, and the investigator maintained privacy and confidentiality through interviews and data security. Furthermore, member checks were completed with each participant and findings were scrutinized for accuracy by peers informed in qualitative research. Direct quotations from the words of participants supported each theme, and an extensive audit trail was maintained during each step of the research process.

RESULTS

Data were collected from 8 parent interviews. Six participants were mothers from separate family units, and 2 interviews occurred as mother/father pairs (N = 8). Five participants were the child’s biological parent(s), with 2 adoptive and 1 foster parent(s). Age of parents ranged from 24 to 44 years (M = 34.81 years). All parents identified as White and lived in different counties in North Central Appalachia. Three participants reported an average yearly household income of less than \$29,999, 4 were unemployed, and 7 cared for at least one additional child in the home (Table 2).

The majority of children with the acquired disability were male (n = 7), with ages ranging from 2 to 13 years (M = 5.38 years).

Table 1. Excerpt From Data Analysis Table

Categories	Subcategories	Specific Descriptors	Condensed Meaning Units	Subthemes	Themes
Darkness = Suffering from caregiving and ambiguous/nonfinite loss	Awful/Worst experience	“We didn’t know what life would be like ... it was very depressing ...” “We didn’t have a diagnosis. For a while it was real dark ... it was a nightmare.” “My thoughts at first [was] that I was losing my child and I didn’t know what I was going to do to help my other son through it.”	Didn’t know what life would be like Not knowing was a nightmare You don’t know what’s going to happen It was bad ... just had to wait and see Fear of losing child	Not knowing what life would be like and waiting to sec. Uncertainty of recovery and fear of losing their child	Theme 4: Knowing and not knowing the terrifying consequences of loss

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Table 2. Parent Demographics (N = 8)

Variable	n (%)	M
Age, y		34.81
Relation to child		
Biological parent	5 (62.5)	
Adoptive parent	2 (25.0)	
Foster parent	1 (12.5)	
Marital status		
Single	2 (25.0)	
Married	5 (62.5)	
Partnered	1 (12.5)	
Annual household income		
<\$29 999	3 (37.5)	
\$50 000-59 999	1 (12.5)	
\$60 000-69 999	2 (25.0)	
\$70 000-89 999	1 (12.5)	
>\$90 000	1 (12.5)	
Employment status		
Full-time	3 (37.5)	
Self-employed	1 (12.5)	
Unemployed	4 (50.0)	
Education level		
High school diploma	4 (50.0)	
Associate degree	1 (12.5)	
Bachelor's degree	2 (25.0)	
Master's degree	1 (12.5)	

Time since injury ranged from 12 to 128 months ($M = 52.12$ months, $Md = 39$), averaging about 4.3 years. Half ($n = 4$) of the disabilities experienced by the children were acquired from injury (traumatic or anoxia to the brain), while the other half ($n = 4$) resulted from unexpected illness or disease. Half of the children used a wheelchair and required medications and oxygen in the home, while 3 children used a ventilator and required enteral supplementation through a feeding tube.

The predetermined categories of unveiling, darkness, and light from transforming loss provide the organizing framework for the findings from this study. Unveiling is the bridge between darkness and light, where a choice is made to view an experience in a positive way and to find meaning and purpose despite suffering and loss.

Unveiling

Unveiling was defined as the active process of freely choosing meaning within an unchangeable experience, such as the ambiguous/nonfinite loss of a child. When asked about unveiling, participants described making active decisions related to their experience of loss. The condensed meaning units derived from their stories included being strong and fighting for their child, doing what has to be done, making more space, connecting with others, giving grace, watching progress, and seeing good. Three themes emerged from the category of unveiling.

Theme 1: Being strong and overcoming challenges to care

Participants commonly chose strength as a motivator to continue caring for their child. One participant stated, "... you just keep being strong for your kid and they feed off that strength ...," while another shared, "... you never know what you're capable of until you're put in that situation where you have to do what you have to do, and you just do it."

This idea of choosing to do what must be done was a common finding when discussing challenges and day-to-day caring needs. Participants described "going with the flow" and "not sweating the small stuff" as catalysts for navigating the caregiving experience; many emphasized the importance of taking it one day at a time.

We've made it this far and we've always just done what needed to be done and we'll continue to do that.

As soon as I knew he was coming home from the hospital ... whatever I need to do is what I'm going to do.

Theme 2: Creating a life space of connecting with others and giving grace

When asked about significant choices or decisions that were made in caring for their child, many participants described choosing to physically alter their living space or deciding to make a life change to accommodate their child's needs.

“We bought a bigger house ... so he could have a room to himself....

I ended up quitting my job ... and did some alterations to the house.

I have not returned to work ... we put some things on hold.

In addition to creating space, choosing to reach out and connect with others was a way to feel less alone and gain a sense of community. One parent shared, “I think what helped me the most was reaching out to online groups of people in similar situations.... I wish I would have reached out sooner.”

Choosing to focus on self and learning to give grace were other common threads associated with the unveiling process. One parent said, “... it’s okay to be sad about the things that he or I have missed because of the disability without feeling guilty,” while another shared, “I had to fix it, or it was all going to fall apart ... do a little bit at a time. It’s hard but take a deep breath and give yourself grace.”

Theme 3: Viewing goodness and joy in watching ongoing progress

When asked about finding goodness in caring for their child, participants consistently

referenced the joy found in watching them progress. One parent shared, “...every little thing is amazing to me ... watching his personality bloom ... it’s really been wonderful to watch.” Another stated, “The joys of watching him progress. He’s an amazing kid. He’s survived so many things he probably shouldn’t have and watching him come back from that ... he’s just an amazing kid.”

Two participants shared their experiences of being proud to be their child’s parent. “It makes me proud to be his [dad]. Whenever someone’s like, ‘Whose boy is that?’ Well, he’s mine,” and “...I’m just proud of him. I’m proud to be his mom and watch him overcome and learn.” Many participants chose to find goodness despite the circumstances, frequently referencing that “being here is good enough,” and that their child is “deserving of love and respect like everybody else” (Table 3).

Darkness

Darkness was defined as the suffering experienced with caregiving and the ambiguous/nonfinite loss. When asked about darkness, participants described the suffering experienced from loss and the challenges

Table 3. Themes of Unveiling and Associated Condensed Meaning Units

Theme 1	Being strong and overcoming challenges of care	<ul style="list-style-type: none"> • Keep being strong for your child • Deciding to keep fighting • Continue doing what needs to be done • Getting through day to day • Go with the flow • Make the best of it • Keep going
Theme 2	Creating a life space of connecting with others and giving grace	<ul style="list-style-type: none"> • Making more space to care • Putting some things on hold • Reaching out and connecting • Learning to give grace • Letting go of things that happen • Needing to focus on self
Theme 3	Viewing goodness and joy in watching ongoing progress	<ul style="list-style-type: none"> • Joy and amazement in watching progress • Proud to watch them overcome • Always trying to find the good • Being here is good enough • Deserving of love, appreciation, and respect • Progressing regardless of disability

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associated with care. The condensed meaning units drawn from their stories included uncertainty of recovery, fear of loss, constant monitoring, being on edge, never getting a break, reevaluating expectations, and worrying who will care for their child in the future. As a result, 3 themes emerged from the category of darkness.

Theme 4: Knowing and not knowing the terrifying consequences of loss

When asked to think back to when the loss occurred, participants discussed feelings of uncertainty, fear, and frustration. One parent shared, “We didn’t know what life would be like ... it was very depressing ... dealing with his care and worrying about what to do or look forward to.” Another shared a similar emotional response: “I battled with ... depression, anxiety, pure sadness ... flashbacks.”

Others shared their experiences with loss immediately after the accident or injury.

... her accident ... was the worst thing ... it was an awful experience.

We didn’t have a diagnosis. For a while it was real dark ... it was a nightmare.

I remember him going back to surgery and we didn’t know if he was going to come out or not.

Theme 5: Unrelenting vigilance and being on the edge that weighs on family well-being

Participants discussed what it was like to care for their child in the home after being discharged from the hospital. Many shared that their child needed constant monitoring due to the fragility of their condition, leaving them feeling frazzled and on edge. In addition, the constant state of caring associated with the loss made them feel like prisoners in their own home.

When we first brought him home ... I was on edge. I didn’t sleep. Every sound he made I was wondering if something was wrong.

... he needed to be watched all the time ... I would go a few days without a shower ...

Before [the disability] I worked quite a bit ... now I’m stuck in this box every day ...

Participants shared how overwhelming care needs related to loss impacted every single part of their life. One parent commented on the impact it had on their relationship, “We never get time alone ... this has put a major stressor on our marriage. We actually separated a few years back.” Others shared what it’s like to never get time to themselves,

The hardest part is never getting a break. You can’t pour from an empty vessel without getting recharged.

You can’t help but compare yourself to other people ... seeing parents sitting and the kids playing. That can’t be the case for us. It’s constant.

Theme 6: The unending worry about lifelong care

Many participants worried about what life would look like in the future. Some shared how caring for their child was going to get more difficult. “It’s going to get harder to care for him. He’s going to get bigger ... and we’re getting older.” Others feared who would care for their child if something happened to them.

I carry around the weight of “Will he be okay?” ... and who’s going to care for him if I’m not here. I don’t have a plan.

... how do you decide if something would happen to me or my husband ... I want my health to stay okay to make sure he’s okay.

Many shared what it is like to constantly reestablish expectations and come to realizations about what their child can and cannot do as a result of the loss (Table 4).

... you have all these dreams for your child. Sometimes with disabilities those things will never happen. Reevaluating expectations is challenging and sad.

... trying to accept that life as we knew it was no longer going to be.

Light

Light was defined as finding purpose and meaning despite loss. When asked about

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Table 4. Themes of Darkness and Associated Condensed Meaning Units

Theme 4	Knowing and not knowing the terrifying consequences of loss	<ul style="list-style-type: none"> • Not knowing what would happen • Just having to wait and see • Fear of losing child • Didn't know if child would recover • Frustration not knowing what to do • Afraid to miss something
Theme 5	Unrelenting vigilance and being on the edge that weighs on family well-being	<ul style="list-style-type: none"> • Needing to be watched all the time • Being on edge • Impacted every part of life • Unable to take a break • Stress about broke us • Stuck in house day and night
Theme 6	The unending worry about lifelong care	<ul style="list-style-type: none"> • Reevaluating expectations is challenging and sad • Wanting to stay healthy to care for them • Who will care if something happens • Caring is going to get harder • Nobody can care for child the same

light, participants shared their hopes for the future and the positivity that has come from caring for their children. Condensed meaning units included unlimited possibilities, hope and excitement for the future, closer connections, strengthened relationships, and rewarding experiences. Two themes emerged from the category of light.

Theme 7: Envisioning possibilities and hope for the future

All participants discussed hopes for the future, often commenting on how far their child had already come and shared excitement for future possibilities.

He is a miracle. He is surpassing anything that was anticipated so I don't ever rule anything out with him.

He keeps amazing us with his progress, so I know the outlook on the future is going to be changing.

... the doctors didn't expect her to make it this far and look where she is now ... there is no limitation to what she can possibly do.

Theme 8: Valuing relationships within the family to foster a caring way of being

When asked about the positive experiences in caring for their child, participants

often discussed the purposeful relationships and closeness within the family.

... he has overcome so much, and our family has grown because of what we've experienced.

I think it made my husband and I much closer ... a lot of people just don't understand.

Some parents found purpose by seeing the positive impact it has had on the child's siblings:

... it makes my older children way more sympathetic to kids with disabilities because they live this every day.

... I have another baby who hopefully grows up to be a kind and compassionate human because he has his brother.

Finally, many shared how purposeful and rewarding it is to care for their child (Table 5).

Caring for a child with an acquired disability is so rewarding. It may be difficult and lonely, but it's so special.

... it's the most rewarding thing I've ever done with my life. Nothing I've ever done ... is as rewarding as what I do at home.

DISCUSSION

Through their experiences caring for a child with an acquired disability, parents

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Table 5. Themes of Light and Associated Condensed Meaning Units

Theme 7	Envisioning possibilities and hope for the future	<ul style="list-style-type: none"> • Proving them wrong • No limitations on possibilities • Outlook on future changing • Hope and excitement for future
Theme 8	Valuing relationships within the family to foster a caring way of being	<ul style="list-style-type: none"> • Immediate connections • Closer relationship with spouse • Caring brought family together • Healed family relationships • Family has grown • Caring is rewarding and special

were able to find meaning and purpose by unveiling light in the midst of darkness. This transformation of loss is congruent with the Theory of Meaning, where individuals have the freedom to choose life purpose despite suffering. Suffering is a subjective piece of the human health experience and described as all-consuming.²¹ Participants related their suffering experiences to the darkness found in caregiving and loss. The uncertainty of unknowns related to loss (theme 4), impact of constant caregiving on self and family well-being (theme 5), and worry about life-long care (theme 6) were all-consuming to the participants living this experience. The dynamic fluidity of loss and continued caregiving demands resulted in suffering that was unwavering and unchanged. In the expanded present, darkness was threaded from past to future, and although it never ceased, participants were gradually able to unveil light through active choices and decisions.

Participants shared their experiences with making the choice to view their situation differently. In the Theory of Meaning, freedom to choose describes a person’s autonomous control over their situation and enables them to choose their attitude.²¹ In discovering their strength, participants were able to overcome challenges to care (theme 1). In time, they created a life space that shielded the darkness by connecting with others and giving themselves grace (theme 2). This allowed them to reside in a present that facilitated the ability to see goodness and joy in watching their child’s progress (theme 3). Although

the unveiling experience was slow and took effort, freely choosing the way they viewed their situation allowed them to see purpose and meaning in their lives. Unveiling is perhaps the most important core quality in the concept, as it serves as the bridge between darkness and light.

Through the process of unveiling, participants began to see meaning and purpose. Life’s purpose is described in the Theory of Meaning as the reason for existence. It can be found through individual works, meaningful experiences, or changes in attitudes.²¹ In a sense, light is found at the end of each unveiling process, and its existence extends well into the future. Light is not unveiled all at once but discovered gradually through chipping away at the darkness. Participants were able to see glimpses of light in the present when thinking toward the future. Their experiences through the process of unveiling enabled envisioning possibilities and hope for the future (theme 7). They found purpose and meaning in both caregiving and loss through the positive change in relationships within the family (theme 8).

In the literature, parents have described caregiving as fear-inducing, stressful, and tiring.²⁶⁻²⁸ Participants reported the need to monitor their child around the clock, afraid they will miss something. This interrupted routines and sleep, leaving them feeling unbalanced and like their life was upside down (theme 5). There is further evidence to support caregiving to be perceived as unpredictable and time-consuming.²⁹ Participants

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battled with not knowing what life would be like after the disability and uncertain of whether their child would recover. There is evidence from theme 4 to support the unknowns associated with consequences related to loss. Participants shared that it is difficult for them to get a break due to the lack of support from others knowledgeable and trained to care for their child, supporting theme 6 related to the worry of lifelong care.

Caregiving experiences were further complicated by ambiguous/nonfinite loss. Navigating this loss is associated with feelings of uncertainty, disappointment, and hopelessness.^{14,15} Participants reported trying to come to terms with false hope and feeling sad when realizing that some of the wishes and dreams they had for their child would never come true. They constantly felt the need to reevaluate expectations based on the current status of their child. This is evident in theme 4, where the consequences associated with an ambiguous/nonfinite loss were terrifying and unknown.

However, darkness associated with caregiving and loss was accompanied by unveiling and light as participants actively worked to uncover meaning in their experiences. There is evidence to support that parents are able to transcend loss using personal enrichment, family cohesiveness, and resilience.¹¹ Many participants experienced enrichment through the joy of watching their child progress and found goodness in hope for the future (themes 3 and 7). They often shared that caring for their child is something unique and special for their family, thus enhancing relationships and bringing them closer together. This is seen in theme 8, where value is found through caring relationships within the family. Unveiling meaning in loss is often accomplished through increased strength, enhanced connections, and helping others.^{30,31} Participants reported using strength to overcome challenges and felt a sense of accomplishment when adjusting to caregiving demands and demonstrating mastery in skills related to complex care. This is supported by theme 1, where parents'

strengths helped them overcome challenges of care. Many participants shared that a turning point came when meeting other parents and families that shared similar experiences. This allowed them to share their frustrations, successes, and tips on providing care and overcoming loss. Eventually, they became confident in their knowledge, skills, and expertise to help other families and spread awareness to the community regarding their experiences. This is supported by theme 2, where choices were made to connect with others and create a safe space to care.

Implications

Findings suggest the need for future research specific to these themes. For example, a phenomenology study derived from theme 1 could examine the lived experiences associated with being strong and overcoming challenges to care. This may provide insight into how parents choose to make different decisions in their caregiving. Another example associated with theme 4 would be a focus group study using content analysis to better understand unknowns related to consequences of loss. Findings may reveal how parents view an ambiguous/nonfinite loss and offer direction on how to better help them grapple with shared, difficult experiences. Finally, further research related to diversity, inequity, and social determinants of health within family systems may provide deeper insight into the impact of accessibility and affordability of resources on parent and child health outcomes.

Providers caring for children with acquired disabilities should anticipate specific needs related to the parents and families living these experiences. Enhanced therapeutic communication extending beyond cognitive and skill-based learning may provide parents with psychosocial support as they attempt to navigate this loss. Providers also have the unique ability to familiarize families with community-based resources and support groups, which could offer reassurance by connecting them with others (theme 2). Understanding the

worry of lifelong care (theme 6) further supports the need for expanded transitions of care models and increased collaboration between providers from hospital to home.

Enhanced discharge planning related to the acute care setting could enhance the preparation for caregiving and navigation of loss at the time of illness or injury. Recent findings show that parents in the PICU experience profound symptoms of depression, anxiety, and fear coupled with decreased perceived support from others.³² Participants in this study revealed that suffering began at the time the disability occurred, supporting the need for enhanced support, frequent debriefing, and trauma-informed care in the inpatient setting. Furthermore, participants who were interviewed were, on average, 4 years out from the onset of disability, affirming the need for extensive follow-up care and allocation of community-based resources. Improvements in policy related to home health nursing or respite care could minimize the perceived caregiving burden and allow parents and their families to have time to grapple with the loss. Finally, enhanced fiscal resources at the state and federal levels could diminish burdens associated with care, by compensating parent or family caregivers for time dedicated to caring to reduce the need for continued full-time employment outside the home.

Limitations

The use of preexisting theory posed the risk for a predetermined bias of the investigator and may have threatened the objectivity

and confirmability of the findings.²³ Furthermore, questions and probes asked during interviews could cue participants to answer questions in a certain way that satisfy the investigator's preference. Finally, transferability of findings is limited in qualitative research, narrowing the applicability of the findings to a small population. The processes used for trustworthiness (credibility, transferability, dependability, and confirmability) as well as having multiple qualitative research experts involved in the research process, particularly data analysis, are believed to have mitigated these potential limitations, but they must be acknowledged.

CONCLUSION

Findings related to the experience of parents caring for a child with an acquired disability are grounded in the knowledge base of nursing and consistent with previous literature related to caregiving, loss, and meaning. The core qualities of unveiling, darkness, and light within the concept of transforming loss are coherent with the concepts and assumptions within the Theory of Meaning,²¹ describing the active process of discovering meaning and purpose despite suffering. These findings offer implications for future practice, research, and policy change to support parents and their children with acquired disabilities through this transformative experience to improve their health, healing, and well-being and further support transforming loss for its use in nursing knowledge development.

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