

# Direct care staff and parents'/legal guardians' perspectives on end-of-life care in a long-term care facility for medically fragile and intellectually disabled pediatric and young adult residents

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## ABSTRACT

*Objective:* Children and young adults with severe disabilities and their families are faced with enormous challenges throughout the lifespan, including admitting the child to a long-term care facility (LTCF) and making end-of-life (EOL) care decisions. While children are residents of these specialized LTCF, the majority of their daily care, even up until death, is provided by nursing aides or habilitation aides (HAs) with limited training and educational backgrounds compared with other licensed healthcare providers. The purpose of this study was to determine the impact of a resident's EOL experience on the primary HAs and parents/guardians.

*Method:* Thirty-five resident deaths occurred at Hattie Larlham Center for Children with Disabilities (HLCCD) between January 1, 2006 and February 28, 2009. The HAs and parents/legal guardians were identified for each death and invited to complete three surveys per resident (FAMCARE, Impact of Events Scale (IES)-revised, and Perspective on End-of-Life Care) to assess their experience. There were 112 surveys mailed to 62 HAs and 47 surveys mailed to 47 parents.

*Results:* Forty-two surveys were returned from 18/62 HAs (response rate 29%) and 11/47 parents/legal guardians completed the surveys (response rate 23%). The FAMCARE survey found that parents were more satisfied with the EOL care than were the HAs. The IES-revised found no difference in traumatic responses from either group. Comments from the Perspective on End-of-Life Care survey were analyzed qualitatively for common themes including pain control, respect, decision making, environmental needs, resources, and support.

*Significance of results:* Because of a low response rate, it was difficult to draw significant conclusions; however, several interesting trends were noted regarding the number of deaths HAs experienced, satisfaction with care, and distress. The special needs of this population and their caregivers can provide crucial insights into interventions (e.g. chaplaincy support,

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debriefings, anticipatory counseling, environmental changes) that might be of benefit for any caregiver or parent of a child with a long-term, chronic condition, particularly involving developmental disability.

**KEYWORDS:** End of life, Long-term care, Pediatrics, Medically fragile persons

## INTRODUCTION

Children and young adults with severe disabilities and their families are faced with enormous challenges throughout the lifespan, including admitting their child to a long-term care facility (LTCF) and making end-of-life (EOL) care decisions. Often these patients are unable to make decisions on their own, and parents, siblings, or guardians are faced with difficult decisions regarding medical care that they must resolve on behalf of their loved ones.

Life expectancy among children born with mental and physical disabilities has been increasing, in part because of advances in medical technology (Strauss et al., 2007). A subset of these children have special healthcare needs and are considered medically fragile, that is, they have complex chronic conditions involving multiple organ systems requiring medical specialists, technological supports, and community services (Gordon et al., 2007). In general, these patients are dependent on medical technology (e.g., gastrostomy tube, tracheostomy, invasive or non-invasive ventilation, urinary catheter) and care supports to sustain life or prevent further disability (e.g. suctioning, tracheotomy care, tube feeding, seizure intervention, and oxygen support). Patients who are considered to be severely medically fragile require intensive care and are more likely to be residents of LTCFs until death. Often these patients can live in a LTCF for  $\geq 20$  years with varying degrees of family involvement. Many of these residents are entering adulthood, but all have had a childhood onset of their disability. Most have severe-to-profound intellectual impairments, have limited mobility and communication, and rely on caregivers for all activities of daily living.

The majority of a resident's daily care at a LTCF is likely to be provided by nursing aides or habilitation aides (HAs) who may have limited training (beyond internal training) and educational backgrounds compared to other licensed healthcare professionals (e.g., nurses, allied therapists). It is not unusual for HAs to work  $>40$  hours per week because of staffing shortages and the attraction of overtime wages. The HAs are often responsible for 4–6 residents during the day and 8–12 residents during the night. They typically provide the majority of the resident's daily care and may do so until the resident's death (Brazil et al., 2004). Therefore, given the HAs' substantial investment in the lives of these patients, they provide a

unique perspective on palliative and EOL care issues. The purpose of our study was to determine the impact of residents' EOL experience on their primary HAs and their parents/guardians.

## METHOD

### Subjects

The Hattie Larlham Center for Children with Disabilities (HLCCD) is a specialized LTCF for pediatric and young adult residents with neurologic impairments and intellectual disability in the severe-to-profound range, who are considered medically fragile. The HAs providing daily care are unlicensed, internally trained individuals who have at least a high school education and pass required criminal and drug screening.

We identified all HLCCD residents who died between January 1, 2006 and February 28, 2009 and their parents/legal guardians. A chart review was performed to determine which HAs provided care to the resident  $\geq 5$  days during the last 30 days prior to the resident's death or hospital admission if the admission was  $>30$  days. This study was approved by the Akron Children's Hospital Institutional Review Board and HLCCD Human Rights Committee; NCT00724646.

### Study Design

All eligible participants were contacted via telephone to inform them about the study. Three surveys, one internally developed (Perspectives on End-of-Life Care) and two validated surveys (FAMCARE and Impact of Events Scale-revised [IES-R]), were mailed to their homes, along with a cover letter explaining the study, and postage-paid return envelopes. The Perspectives on End-of-Life Care survey (40-item scale for HAs; 44-item scale for parents/legal guardians) was developed by the study team to focus on six domains: resident's needs, creating a homelike environment, supports for families, providing quality care processes, recognizing death as a significant event, and sufficient institutional resources. The FAMCARE scale is a 20-item scale designed to measure family member satisfaction, focusing on four areas: availability of care, physical patient care, psychosocial care, and information giving. The IES-R is a 22-item scale designed to measure subjective distress

relative to a specific event, focusing on three dimensions: intrusion, avoidance, and hyperarousal.

For the HAs who provided care to more than one resident, one set of surveys per resident death were provided. Each individual parent/legal guardian received a set of surveys. Participants were requested to complete and return the surveys within 2–3 days of receipt. Follow-up phone calls were made if surveys were not received within 2 weeks. Consent was implied by voluntary return of the completed surveys. Undeliverable surveys were re-mailed when new addresses were available.

Participants were asked to indicate, via a response card returned with the completed surveys, if they would be interested in participating in a focus group to be conducted at the HLCCD main facility. The intent was to conduct separate focus groups for HAs and parents/legal guardians, facilitated by a PhD clinical psychologist (author EB), and to record the 1.5 hour sessions for thematic analysis.

### Statistical Analysis

Study participants were described overall and by group with descriptive statistics. Likert-scale values for each survey question were described with frequencies by group and overall. Scores were flip-coded for the analysis so that a higher score indicated greater satisfaction, very satisfied (5) to very dissatisfied (1). Responses for the HA and parents/legal guardians were analyzed to determine if there was a difference in response by group to the Likert-scale survey tool. Additional comments provided to all Likert-scale questions on the Perspectives of End-of-Life Care survey were reviewed by two independent statisticians for qualitative analysis to identify major thematic elements.

## RESULTS

### Demographics

Between January 1, 2006 and February 28, 2009, 35 resident deaths occurred either at HLCCD or a hospital. These children had been admitted to HLCCD between 0 and 13 years of life; 8 (23%) were  $\leq 5$  years of age at time of HLCCD admission. Length of residency until death ranged from 8 to 26 years and residents were 10–29 years of age at death. Causes of death included respiratory failure/pneumonia, sepsis, intractable seizures, and complications of underlying disease state/syndrome.

One parent declined participation prior to mailing; therefore, surveys were mailed to 47 parents/legal guardians. Eleven surveys were completed and returned for 10 unique resident deaths for an

**Table 1.** Survey participant demographics

Characteristic	Parent/Legal guardian <i>n</i> = 11	Habilitation assistant <i>n</i> = 18
Female	9 (82%)	14 (78%)
Age (mean)	55.6 ± 15.2 yrs	36.7 ± 13.5 yrs
Race		
Caucasian	9 (82%)	17 (94%)
Marital status		
Married	10 (91%)	NA
Divorced	1 (9%)	NA
Highest education		
High school	3 (27%)	12 (67%)
Vocational school	3 (27%)	3 (17%)
Undergraduate degree	1 (9%)	2 (11%)
Graduate degree	4 (36%)	1 (5%)
Employment		
Service/personal care	4 (36%)	NA
Self-employed	2 (18%)	NA
Professional careers	5 (45%)	NA

overall parent response rate of 23% (see Table 1 for demographic data). Responses regarding marital status indicated that 91% of the participants were married at the time of survey; in addition, two parents had been divorced in the past and related this to the child's disability. One parent/legal guardian had three other children at home and seven had one or two other children at home. The majority of parents (82%) lived  $\leq 70$  miles of HLCCD, and only two parents lived  $\geq 1000$  miles away. Eight parents indicated how frequently they visited their child (one parent twice per year; seven parents 1–15 hours per week). Barriers to visitations included other family obligations, work responsibilities, and transportation issues. The majority of parents/legal guardians had their children admitted to HLCCD because of inability to provide the necessary care at home.

Sixty-two HAs were identified who cared for a resident  $\geq 5$  days within the last 30 days prior to his/her death. A total of 112 surveys were mailed to the HAs; 3 HAs received 5 surveys, 3 HAs received 4 surveys, 7 HAs received 3 surveys, 16 HAs received 2 surveys, and 33 HAs received 1 survey. Forty-two HA surveys were returned from 18 individual HAs, for an overall response rate of 29% (see Table 1 for demographic data). The majority of the HAs (88%) were still employed at HLCCD at the time of the survey. Length of care provided to the specified resident prior to death ranged from  $< 1$  year (40%) to  $> 10$  years (33%). Five HAs indicated that they were in the room when the resident died; seven attended a

memorial service and four participated in the memorial service. Two HAs indicated that they had accessed bereavement support resources outside of work. Fourteen HAs answered the question regarding how many resident deaths they had experienced in the past 5 years; two indicated  $\geq 20$  deaths, four had experienced 15–20 deaths, two had experienced 10–15 deaths, three had experienced 5–10 deaths, and three had experienced  $\leq 4$  deaths; overlap is the result of open-ended responses.

### FAMCARE Survey Results

Responses to the FAMCARE were received from 17 HAs and 11 parents (see Table 2 for results). Higher scores for each question indicate greater satisfaction (1 = very dissatisfied, 5 = very satisfied). The mean overall score for all responses was  $3.9 \pm 0.7$ . Parents gave the highest ratings (mean 4.6) for doctor's attention to patient's description of symptoms, nursing availability, and family inclusion in treatment and care decisions; the lowest ratings (mean 4.1) were given for patient's pain relief and speed with which symptoms were treated. HAs gave the highest ratings (mean 4.2) for nursing availability and coordination of care whereas the lowest rating (mean 3.3) was given for information about patient prognosis. The Mann–Whitney test was used to compare differences between the FAMCARE satisfaction scores for the parents (median 3.8) and aggregate HA scores (median 4.2),  $p$ -value = 0.009, indicating that the

parents were more satisfied with the care provided than were the HAs.

### IES-R Survey Results

IES-R responses were received from 18 HAs and 11 parents (see Table 2 for results). Higher scores for each question indicate greater response (0 = not at all, 4 = extremely). The Mann–Whitney test was used to compare HA and parent scores for each domain; none of the intergroup comparisons reached statistical significance, suggesting no difference in traumatic responses from either group.

### Perspectives on End-of-Life Care Survey Results

Perspectives on End-of-Life Care surveys were received from 18 HAs and 11 parents/legal guardians. Responses for the majority of the questions were based on a six-point scale ( $-3$  = strongly disagree,  $+3$  = strongly agree) whereas two questions were answered on a three-point scale ( $-1$  = too little for the resident to  $+1$  = too much for the resident) (see Table 2 for results). There was agreement between the two statisticians regarding categorization of the common themes for the qualitative analysis of the comments, although the emerging themes did not necessarily fit the domains in which the questions were provided (themes and comments are outlined in Table 3).

**Table 2.** Results for the FAMCARE, IES-R, and Perspectives on End-of-Life Care surveys

Survey	HA aggregate	Parents/Guardians	Results <sup>a</sup>
FAMCARE <sup>b</sup>	$n = 17$	$n = 11$	
Satisfaction of care mean (SD)	3.7 (0.7)	4.4 (0.5)	
median	3.8	4.2	$p = 0.009$
IES-R	$n = 18$	$n = 10$	
Intrusion mean (SD)	1.3 (0.9)	1.6 (1.3)	
median	1	1.5	$p = 0.707$
Avoidance mean (SD)	0.9 (0.8)	1.2 (1.1)	
median	0.7	1.3	$p = 0.550$
Hyperarousal mean (SD)	0.6 (0.8)	0.9 (1.0)	
median	0.3	0.7	$p = 0.877$
Perspectives on end-of-life	$n = 18$	$n = 11$	NA
Resident's needs	1.9 (0.6)	2.2 (0.9)	NA
Creating a home-like environment	1.9 (0.8)	2.2 (0.9)	NA
Supports for families	1.6 (0.6)	1.6 (0.8)	NA
Providing quality care processes	0.4 (0.8)	1.6 (0.6)	NA
Life sustaining treatment	-0.05 (0.2)	0.1 (0.3)	NA
Advance directives	1 (1.6)	2.3 (1.2)	NA
Recognizing death as a significant event	-0.4 (1.4)	0.6 (2.3)	NA
Sufficient institutional resources	0.8 (0.7)	1.1 (1.0)	NA

<sup>a</sup>Mann–Whitney test for FAMCARE and IES-R results.

<sup>b</sup>FAMCARE scores flip-coded for analysis.

IES-R, Impact of Events Scale–Revised.

**Table 3.** Summary of common themes and respondent comments from the Perspectives on End-of-Life Care Survey**Habilitation assistants**

Importance of patient comfort and respect

*I did all I could to make her comfortable- repositioning, keeping, clean, dry, etc*

*We brought in comfortable chairs, recliner- lighting was low and we played [patient's] CDs of relaxation music-music that was often played for her*

One-on-one care was a resource to provide necessary and sufficient care

*They provided one aide to sit one-on-one with her.*

Not satisfied with patient comfort but not something anyone could control

*Sometimes you felt helpless because no matter what you did you could tell he was still uncomfortable*

Felt strong connection to their patients, part of their family and loved the patient

*I couldn't help but treat individual with respect- he would tug on my heart strings. I made sure his O2 was on properly- that he was clean and dry at all times and held and loved as much as possible*

*The children that I tend to are family to me. Even more so than some of my actual family.*

*We always get attached to child and I always think of them as my own so I take care of them like I would want my child taken care of.*

Felt they were part of the patient's family and treated that way

*I knew the family well and I felt like they were part of my family so I was able to be sensitive towards their feelings.*

*The family actually had a nurse call me at home and ask me if I could meet with all them after his death. I drove over an hour and met with them in private where we cried and at times laughed and just talked and they expressed their sincere appreciation to me and her.*

Importance of nurturing relationships with patient's family and respecting their wishes

*When I did talk to his grandma she wanted us to pray. So I did, we all did.*

*[Patient] was in the hospital the last couple of days of his life and he was surrounded by and held by family members- I was not at the hospital because I felt his family needed this time with him.*

Grief influenced by connection to patient's family and length of time caring for patient

*Because [patient] was not real "responsive" and her family not being very involved, it wasn't a loss like some of the deaths are*

*I loved [patient] but I hadn't been there long enough [to feel like they had lost a family member].*

Considered some parents very devoted and noticed others were not as involved

*I've never seen more devoted parents*

*These parents were awesome and there was no doubt in my mind that the choices they made were definitely in their child's best interest.*

*I think they could have spent more time with him.*

*In the years I cared for individual- I only had contact with family 2 times.*

Viewed death as part of the job and did not allow it to interfere with other responsibilities

*While I was upset about losing [patient], I knew I had other individuals to take care of to the best of my ability.*

*My family is my life and I can't let anything interrupt my duties.*

Even though part of the job, deaths were often unexpected and happened suddenly

*She had been sick so many times and would always recover so it was rather unexpected- we'd assume she'd get better.*

*[Patient's] passing came suddenly and was somewhat unexpected.*

Experienced sense of loss and grief

*When you walk in your room everyday and they're not there, you definitely miss them.*

Generally viewed medical staff and other HAs positively

*The doctor always asks us if we can do any more for individual or if we have any suggestions.*

*The nurses I've worked with are very good at what they do and care deeply for the individual.*

*There were times when HAs didn't want to take care of [patient].*

*On the night of their death the mother wanted us with her till the father came and the nurses made us leave her by herself.*

Bereavement support appeared to mostly be obtained from other staff members, not the organization

*My co-workers were very supportive and my co-workers helped me a lot. This was my first death while working here.*

*From the HAs because we are like a family and they have been through it themselves so they are the best one's to talk to.*

Not aware of available support and some did not feel supported by employer

*I didn't know that we had any outside of that we use for family.*

**Parents/Legal guardians**

Good communication around advanced directives

*Those issues were discussed many times especially at her evaluations.*

*This was discussed many times before and the day we were notified of her illness.*

Attended memorial services and appreciated support from staff

*The memorial was so amazing. There were a lot of staff and sharing time that was very healing.*

*Our family was lucky to have HLCCD in our life at this time. We would have been lost without them.*

Several participated in the hospital's bereavement group

Most expressed positive comments about child's care

*Someone was always there providing special care and letting [patient] know how much she was loved.*

Continued

**Table 3.** *Continued*


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	<i>It's hard to really know since she could not communicate. I knew for certain the doctor and staff did everything possible to make her comfortable.</i>
	<i>Not always. He liked to ride in his wheelchair and sit in a recliner. These two activities were seldom done.</i>
	Several mentioned their child's limitations
	<i>We didn't know if he ever knew, even for a minute, what was going on.</i>
	Felt supported in spending time with their child at his/her end of life
	<i>It was important to everyone that I was there.</i>
	<i>They cleared the room and everything focused around [patient].</i>
	Deaths were expected to some extent for some parents and unexpected for others
	<i>[Patient] had been very sick the last 6 months.</i>
	<i>I was told at least a dozen times over [patient's] life that he was actually dying at that particular time.</i>
	Differing opinions on where their child should die
	<i>I felt it better for me as her mother. I think it would have been too emotional at HLCCD. And I had to make sure [patient] did not suffer during her last days and felt the palliative care team at [hospital] would be better suited.</i>
	<i>Yes, at HLCCD and not at a hospital. She was surrounded by everyone who knew and loved her.</i>
	Mostly positive feelings towards HAs and nurses
	<i>They were just like family.</i>
	<i>Yes, they may have been overworked but they wanted to do anything possible for [patient].</i>
	<i>[Patient's] HAs came to the hospital during [patient's] "end of life" and felt like I was the "bad guy" at times.</i>
	Very positive feelings towards physicians and nurse practitioners
	<i>I received much needed emotional care and the "medical aspect" of [patient's] death and the spiritual care I needed.</i>
	<i>Both were wonderful and did anything I asked of them.</i>

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One theme that emerged strongly from the HA comments regarded the devotion of parents to their child. The HAs noted the importance of nurturing relationships with the resident's family, whereas some felt that they did not know the parents very well. Although the HAs generally had a positive view of the other healthcare providers and HAs for the patients, conflicts and issues did arise. Several parents commented on the care their child received, both positive and negative, and felt support for spending time with their child. Generally parents had positive feelings toward the HAs, nurses, and physicians/nurse practitioners.

Six HAs and six parents indicated that they would be interested in participating in a focus group. However no HAs attended and only one parent attended; therefore, these comments were treated as additional comments to the survey.

## DISCUSSION

The number of children and young adults living in LTCFs is small, and estimates are difficult to establish; whereas there are <100 pediatric LTCF's (~10,000 total residents), there are estimates that as many as 6,000 children and adolescents <21 years of age live in adult nursing homes in the United States (Shapiro, 2010). Family involvement is highly variable among residents of LTCFs. For example, at HLCCD, only ~50% of the families are regularly involved and only ~25% visit regularly.

To our knowledge, there are no studies or validated surveys focusing on the EOL experience for residents

of pediatric LTCFs as assessed by direct care providers or families (Brazil et al., 2004, Vohra et al., 2006, Grossberg, 2008). One study noted that caregivers of children with physical disabilities experience a decrease in physical functioning that may be related to pain severity and mood, but did not address the emotional impact of care (Tong et al., 2002). Another study, performed in an acute care children's hospital, noted a high rate of burnout and compassion fatigue among care providers (Robins et al., 2009). Several studies have examined the effects of EOL on caregivers in the adult LTC environment or in the acute care setting, but none have sought to examine the effect on families and caregivers in the pediatric LTC environment (Wetle et al., 2005, Rickerson et al., 2005, Hirakawa et al., 2009, McClement et al., 2009).

During the 37 months of the study there were 35 deaths, many of the residents had lived well into the second and third decades of life, which in most cases exceeded predicted life expectancy. Therefore, individual HAs could be providing care to these residents for several years and develop a relationship with the resident and family members. A total of 159 surveys were mailed to the HAs and parents; however, response rates were low in both groups, making it difficult to draw significant conclusions. Nonetheless, some of the observed trends are meaningful in constructing a strategy to address the important challenges that arise in this care environment.

The HAs had to process a substantial amount of loss with ~44% experiencing >10 deaths during their employment. One third of the HAs had provided

care for >10 years at the time of the resident's death, indicating that in many cases the HA had had a long-term relationship with the resident; often the length of this relationship exceeded the amount of time the child had lived at home. The IES-R measures demonstrated some level of distress in parents and HAs based on total scores >33 (Creamer et al., 2003), but the difference was not statistically significant although the parents had slightly higher impact scores on the IES-R scales. In the experience of the authors working with these families, several hypotheses appear likely. For one, these families may have distanced themselves from their children in order to attend to the rest of their families and/or minimize pain and suffering over their decision to have their children placed. Also, families are often called on numerous occasions for near-death scenarios (as quoted by one parent) and may have desensitized themselves to the emotional trauma, and in some cases the death may actually be experienced as a relief. The HAs may have minimized the impact of the deaths through denial or may have become desensitized over time.

The FAMCARE scores demonstrated overall satisfaction with the care provided, with the parents indicating feeling satisfied or more than satisfied in each of the four areas. The HAs' lowest rating was regarding information provided about the patient's prognosis, suggesting they may not have been aware of the severity of the illness of their resident. The reasons for this are also multifactorial, but may have been exacerbated both by HAs' not being present during medical rounds (particularly on second or third shift) and/or by poor communication with the nursing staff. It has been the observation of the authors that like parents, the HAs may employ defenses that serve to mitigate the reality of their resident's illness.

Several HAs reported they wanted more information from the nurses and doctors and would have liked more emotional support from the medical staff. As noted in several of the comments, staff shortages at all levels appeared to affect communication and the ability to provide compassionate care. Strategies to maximize retention, therefore, would likely positively impact the dying process for staff and families. Staff shortages may also have contributed to poor attendance at the focus groups. For families, distance may have provided additional difficulty in attending the focus group, as the facility is in a rural area without access to public transportation. The lack of attendance may also represent powerful yet unrecognized grief experienced by HAs and families.

Results from the Perspectives on End-of-Life Care tool demonstrated that both parents and HAs felt the residents' needs in terms of pain control, respect, and decision making by parents and guardians were adequately met. The results suggested similar satisfaction

with the environmental needs, resources, and supports for families at EOL. The HAs, however, felt that there were inadequate emotional supports after the residents' deaths and did not feel comfortable accessing bereavement support resources. It has been the authors' experience that formally organized support groups or individual counseling through employee assistance programs have been poorly attended. Although employees do attend and participate in memorial services, they appear to garner more emotional support informally through their fellow employees.

As noted previously, our study was limited by the poor response rate from HAs and parents, by the retrospective nature of the inquiry (including recall bias), and by the nature of a survey study. Nevertheless, the results detailed here—particularly the open-ended comments—do provide important insight into the perspective of caregivers and parents of the EOL experience. On the basis of the information gained herein, concrete improvements in facility-based care could be instituted to address some of the distress uncovered. These might include: chaplaincy support for families and caregivers; informal but regular debriefings; better inclusion of staff in medical updates and rounds; anticipatory counseling and preparation for families and caregivers of residents who have exceeded their predicted lifespan; environmental engineering to allow families to be with their children throughout the dying process; improved education in recognition of the near-death and dying process to allow more open conversation about plans and wishes; and measurement of staff distress to prospectively and proactively identify staff members who would benefit from individual and/or organizational therapeutic interventions.

## CONCLUSION

This study represents the first attempt of its kind to elucidate the special challenges inherent in the care of children and young adults who die in the LTCF setting. Although the numbers are small, the special needs of this population and their caregivers can provide crucial insights into interventions that might be of benefit for any caregiver or parent of a child with a long-term, chronic condition, particularly with developmental disability. Future research should focus on developing instruments that adequately measure distress in this population, further defining variables that either aggravate or ameliorate distress for both families and caregivers in this unique situation, the role of an interdisciplinary pediatric palliative care team in the care of this population, and outcomes of specific interventions designed to relieve parental and caregiver suffering.

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