

Considerations About Hastening Death Among Parents of Children Who Die of Cancer

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Objectives: To estimate the frequency of hastening death discussions, describe current parental endorsement of hastening death and intensive symptom management, and explore whether children's pain influences these views in a sample of parents whose child died of cancer.

Design: Cross-sectional survey.

Setting: Two tertiary-care US pediatric institutions.

Participants: A total of 141 parents of children who died of cancer (response rate, 64%).

Outcome Measures: Proportion of parents who (1) considered or (2) discussed hastening death during the child's end of life and who endorsed (3) hastening death or (4) intensive symptom management in vignettes portraying children with end-stage cancer.

Results: A total of 19 of 141 (13%; 95% confidence interval [CI], 8%-19%) parents considered requesting hastened death for their child and 9% (95% CI, 4%-14%)

discussed hastening death; consideration of hastening death tended to increase with an increase in the child's suffering from pain. In retrospect, 34% (95% CI, 26%-42%) of parents reported that they would have considered hastening their child's death had the child been in uncontrollable pain, while 15% or less would consider hastening death for nonphysical suffering. In response to vignettes, 50% (95% CI, 42%-58%) of parents endorsed hastening death while 94% (95% CI, 90%-98%) endorsed intensive pain management. Parents were more likely to endorse hastening death if the vignette involved a child in pain compared with coma (odds ratio, 1.4; 95% CI, 1.1-1.8).


Conclusions: More than 10% of parents considered hastening their child's death; this was more likely if the child was in pain. Attention to pain and suffering and education about intensive symptom management may mitigate consideration of hastening death among parents of children with cancer.

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WHILE PROVIDING CARE for patients with advanced life-threatening illnesses, clinicians may face inquiries about hastening death (HD).^{1,2} Among adults with advanced illness, discussions about HD occur about 10% to 20% of the time, with serious requests taking place only in 2% to 10% of the cases.³⁻⁵ With 2 US states now allowing legalized physician-assisted suicide,⁶ these discussions

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may become more frequent. Attitudes toward HD in noninfant children with life-threatening conditions have seldom been described. The existing reports come from the Netherlands,^{7,8} where euthanasia is legal for infants and children older than 12 years, and although they provide relevant

ethical, legal, and policy considerations, their clinical applicability outside of the Netherlands is limited.

The Institute of Medicine has recommended that HD requests be "fully explored,"⁹ stemming from the understanding that, typically, substantial suffering, which can be uncovered and alleviated, underlies such requests.¹⁰⁻¹² Specifically, hopelessness and psychosocial distress have been associated with HD requests in adult patients.^{3-5,13,14} On the other hand, physical suffering has not been conclusively linked to desire for HD.¹⁴ Instead, imaginary pain, such as pain in others or the prospect of one's own pain, has been associated with lay persons' endorsement of HD vignettes.^{15,16} Similarly, patients who feared uncontrolled symptoms, but not those who had them, were more likely to request HD in Oregon.¹⁷ These findings become particularly interesting when thinking about what may motivate a parent's consideration of HD.

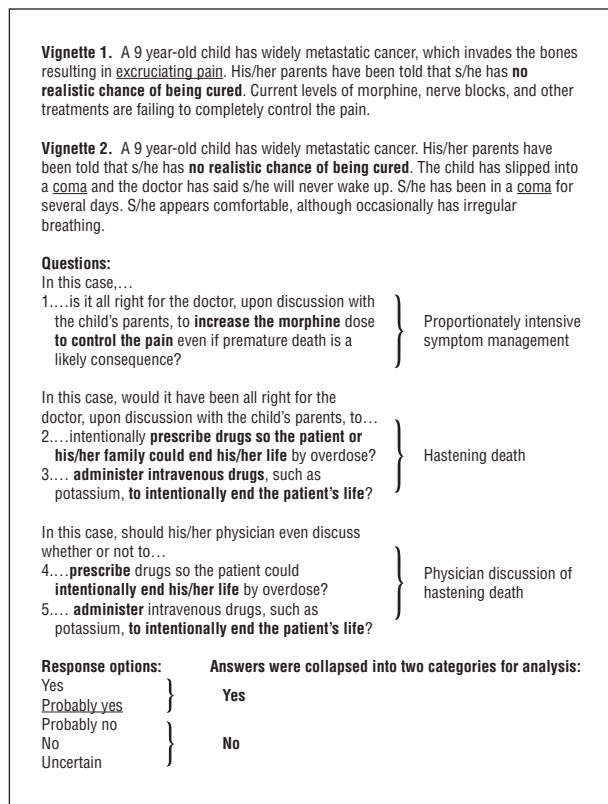


Figure 1. Clinical vignettes about hastening death. Adapted from Emanuel and colleagues.⁴

To better understand consideration of HD by parents of children with cancer and to examine the role of the child's suffering in prompting HD conversations, we asked bereaved parents whether they considered or requested hastening of death during their child's illness and whether different circumstances would have motivated such a consideration. Using clinical vignettes of a child with end-stage cancer, we further examined parental endorsement of HD and their endorsement of proportionately intensive symptom management. Finally, we explored whether the child's pain was associated with past and current HD views.

METHODS

The methods of this retrospective cross-sectional survey have been previously described.¹⁸⁻²¹ From 1997 to 2001, we interviewed parents and physicians of children who died of cancer between 1990 and 1999 and were cared for at the Dana-Farber Cancer Institute/Children's Hospital, Boston, or Children's Hospitals and Clinics, St Paul/Minneapolis. The protocol was approved by both institutional review boards. Permission to contact the family was obtained from the child's primary oncologist. Parents were eligible if they spoke English, resided in North America, and their child had died at least 1 year before contact. Eligible families received a letter of invitation containing either a postage-paid opt-out (Dana-Farber Cancer Institute) or opt-in (Children's Hospitals and Clinics) postcard in agreement with each site's institutional review board requirements. We interviewed 1 parent per family, designated by the family. Two trained interviewers (Caron Moore, RN, MSW, and Carol Collins) and 2 investigators (J. W.-S. and J.W.) carried out all interviews.

Primary physicians denied us permission to contact 19 families, leaving a total of 244 eligible parents. Of 222 parents whom we reached, 141 completed the surveys (response rate, 64%). Responders and nonresponders did not differ regarding child's age at death or diagnosis. Interviews were primarily telephone administered; however, 35 were done face-to-face, based on the parent's request. Interviews were conducted a median of 3.3 years after the child's death (range, 1.1-10.8 years).

PARENTAL SURVEY

The parental survey was a 390-item semistructured questionnaire with most items developed de novo, following guidelines by Streiner and Norman,²² and using focus groups of parents and caregivers.¹⁹ Items evaluated in this text include whether parents ever considered HD ("During your child's end-of-life care period, did you or a family member ever consider asking someone on the care team to give him/her or give you or the family member medications to intentionally end his/her life?"), held discussions about HD ("When your child was receiving end-of-life care, did you or a family member ever discuss intentionally ending his/her life?"), asked someone to proceed with HD ("Did you or a family member ask someone on your child's care team to give him/her medications or to give you or the family member medications to intentionally end his/her life?"), or actually intentionally ended their child's life ("Did a member of your child's care team give you child medications or did you or a family member give him/her medications to intentionally end his/her life?"). We also asked parents whether specific considerations (eg, uncontrollable pain, to control his or her death, or because the child's life was too limited) would have affected their desire for HD for their child (question and response options are shown in text and tables). Finally, we assessed parents' current views about HD were assessed using 2 clinical vignettes (**Figure 1**) adapted from similar ones developed for adult patients.⁴ Both vignettes described a 9-year-old child with widely metastatic cancer and no realistic chance of cure, each with a different end-of-life circumstance: uncontrollable pain (vignette 1) and irreversible coma (vignette 2). For each clinical scenario, we asked parents whether they would endorse intensive symptom management or death hastened by family or physician action and if it would be all right for physicians to raise these topics with families.

Parents were also asked about their child's symptoms, quality of life, care characteristics, and their own experience during the child's last month of life. Location of death and sociodemographic and family characteristics were also collected.

MEDICAL RECORD REVIEW

The child's age at death, sex, diagnosis, and cause of death (ie, disease progression vs treatment-related) were abstracted from medical records.

STATISTICAL ANALYSIS

The analysis was conducted using SAS version 9.1 for Windows (SAS Institute, Cary, North Carolina). Owing to the sensitive nature of the study items, we created a deidentified database for this analysis. Descriptive statistics were used to characterize parents' actual experiences with HD during their child's end-of-life course and their current views about HD. The 95% confidence intervals (CIs) for rates were calculated using normal approximation to the binomial distribution.

Relevant family characteristics associated with consideration of HD during end of life were explored by performing univariate analysis using the Fisher exact test. Univariate associa-

Table 1. Characteristics of Children Who Died of Cancer and Their Parents

| Characteristic | Participants, No. (%) (n=141) |
|--|----------------------------------|
| Study site, state | |
| Massachusetts | 102 (72) |
| Minnesota | 39 (28) |
| Child characteristics | |
| Sex, female | 66 (47) |
| Age at death, mean (SD), y | 10.2 (6.6) |
| Type of cancer | |
| Hematological malignancy | 70 (50) |
| Solid or brain tumor | 70 (50) |
| Cause of death | |
| Disease progression | 110 (79) |
| Treatment-related | 29 (21) |
| Parent and family characteristics ^a | |
| Respondent sex, female | 117 (83) |
| Parental age at child's death, mean (SD), y | 39.3 (7.6) |
| Married at the time of the child's death | 121 (86) |
| White, not Hispanic | 131 (93) |
| College graduate or more | 75 (53) |
| Annual income, ≥\$75 000 (n=139) ^b | 42 (30) |
| Private insurance | 126 (89) |
| Catholic | 65 (46) |
| Not very religious (n=140) ^c | 89 (64) |
| Family experienced prior loss | 110 (78) |
| Prior death associated with a lot or great deal of suffering (n=134) | 41 (31) |

^aDenominator is indicated when it differs from total sample.

^bIncome was collapsed at US \$75 000, representing the 80th percentile of the US annual household income for the survey years (see "Methods" section).

^cCorresponds to response options "somewhat" and "not at all" religious (vs very religious).

tions of family characteristics with endorsement of HD in vignettes were tested using logistic regression models (PROC GENMOD in SAS). The family characteristics examined were race, marital status, education, annual income, health insurance, religion, religiousness, and having had a prior loss. Annual income, originally a 7-category variable, was dichotomized at US \$75 000, based on data distribution; this cutoff point corresponds roughly with the 80th percentile of the US annual household income for the years the question referred to.²³

CONSIDERATION OF HASTENING DEATH DURING THE CHILD'S END OF LIFE AND CHILD'S PAIN SUFFERING

Suffering from pain during the last month of life was an ordinal, 5-category variable (not at all, a little, some, a lot, or a great deal of suffering). To test increasing consideration of HD across the 5 pain categories, we performed the Cochran-Armitage test for trends. To adjust for relevant family characteristics, we ran a logistic regression model including family characteristics with $P < .25$ in univariate analyses. $P < .05$ was required for variable retention. Results are reported as odds ratios (ORs) with 95% CIs.

ENDORSEMENT OF HASTENING DEATH IN VIGNETTES AND PAIN

To explore whether children's pain was associated with bereaved parents' endorsement of HD, we used a multivariate modeling approach. This analysis is a complete case approach based on the 140 parents who responded to the vignettes.

Table 2. Family Characteristics Associated With Parent's Consideration of Hastening Death During the Child's End-of-Life Period

| Family Characteristics ^a | Participants, % | |
|---|-----------------|-----------------|
| | Yes (n=19) | No (n=122) |
| White, not Hispanic | 95 | 93 |
| Married | 95 | 84 |
| College graduate or more | 63 | 52 |
| Annual income, ≥\$75 000 (n=139) ^b | 53 | 27 ^d |
| Private insurance | 100 | 88 |
| Catholic | 16 | 51 ^e |
| Not very religious (n=140) ^c | 84 | 60 |
| Family experienced prior loss | 84 | 77 |

^aDenominator is indicated when it differs from total sample.

^bIncome was collapsed at US \$75 000, representing the 80th percentile of the US annual household income for the survey years (see "Methods" section).

^cCorresponds to response options "somewhat" and "not at all" religious (vs very religious).

^d $P < .05$, Fisher exact test.

^e $P \leq .01$, Fisher exact test.

Endorsement of HD was the main dependent variable. Answers to each HD question (family HD, pain vignette; physician HD, pain vignette; family HD, coma vignette; and physician HD, coma vignette) were collapsed into 2 categories (yes/no, Figure 1) and treated as separate observations. Thus, the unit of analysis was the answer to each HD question rather than each subject's response.

To account for the lack of independence of responses given by the same parent (ie, up to 4 responses per parent), we used generalized estimating equations using PROC GENMOD in SAS to fit 2-level logistic regression models in which the first level represented the answer to each HD question and the second level, the parent. The main independent variable was type of vignette (pain vs coma). Family characteristics with $P < .25$ in univariate analyses were entered into the model and retained if $P < .05$. Results are reported as ORs with 95% CIs.

RESULTS

Table 1 summarizes characteristics of the study population. Parents were predominantly white, married, and college educated; a substantial minority was Catholic, although most were not very religious.

REPORTED EXPERIENCE WITH HASTENING DEATH

Nineteen of 141 parents (13%; 95% CI, 8%-19%) reported that they had considered asking about HD, and 13 parents (9%; 95% CI, 4%-14%) reported having discussed intentionally ending their child's life. Five parents (4%; 95% CI, 0.5%-7%) reported having explicitly asked a clinician for medications to end the child's life, and 3 parents (2%; 95% CI, 0%-3%) reported that their child's life was intentionally ended with medication. In all 3 cases, the medication used was morphine. Parents who reported an annual income of more than US \$75 000 were more likely to consider hastening their child's death, whereas Catholic parents were less likely to do so (**Table 2**). **Figure 2** shows the proportion of parents who considered HD across the 5 categories of suffering from pain during the child's last

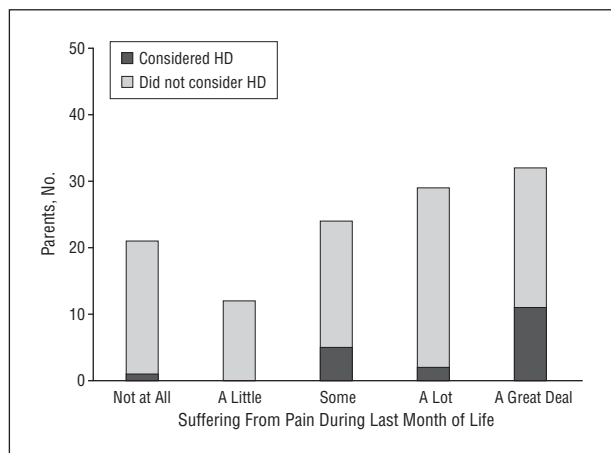


Figure 2. Proportion of parents who considered hastening their child's death across increasing levels of child's suffering from pain (n=138; Cochran-Armitage trend test, $P=.02$). HD indicates hastened death.

Table 3. Circumstances in Which Parents of Children Who Died of Cancer Would Have Considered Discussing Hastening Death

| Variable ^a | Participants, % (95% CI) (n=136) |
|--|----------------------------------|
| Would have considered hastening death under certain circumstances ^b | 36 (28-44) |
| Circumstances | |
| Uncontrollable pain (n=134) | 34 (26-42) |
| Child or parent didn't want child to live this way (n=133) | 15 (9-22) |
| Death was a release from their child's life (n=133) | 15 (9-21) |
| To control his or her death (n=134) | 12 (7-18) |
| Life seemed meaningless and purposeless (n=133) | 7 (2-11) |
| Child's life was too limited (n=134) | 6 (2-10) |
| Didn't want family to see child suffer (n=134) | 1 (0-2) |
| Costs of medical care (n=134) | 1 (0-2) ^c |
| Caring for child was a burden on the family (n=134) | 0 (0) |

Abbreviation: CI, confidence interval.

^aDenominator is indicated when it differs from total sample.

^bThe actual question was, "Given what you know now, can you imagine (other) circumstances in which you might have wanted to ask a member of your child's care team to give him/her medications or give you or a family member medications to intentionally end his/her life?" It was followed by, "May I ask about several circumstances in which you might have done this? (Specify all)."

^cAnswered, "maybe."

month of life. Consideration of HD increased with increasing suffering from pain. The proportion of parents who considered HD increased from 5% when the child had no pain suffering to 26% when the child suffered a great deal from pain (Cochran-Armitage 2-sided exact trend test $P=.02$). These results remained stable after adjusting by high income and being catholic (OR, 1.7; 95% CI, 1.1-2.8; $P=.02$).

CURRENT VIEWS ABOUT HASTENING DEATH

Circumstances in Which Parents Would Have Considered Hastening Death

In retrospect, 36% (95% CI, 28%-44%) of parents reported that they would have considered HD for their child

Table 4. Family Characteristics Associated With Parent's Endorsement of Hastening Death in Vignettes^a

| Family Characteristics ^b | Participants, % | |
|---|-----------------|-----------------|
| | Yes (n=70) | No (n=70) |
| White, not Hispanic | 97 | 89 ^e |
| Married | 87 | 49 |
| College graduate or more | 53 | 53 |
| Annual income, \geq \$75 000 (n=139) ^c | 33 | 29 |
| Private insurance | 91 | 87 |
| Catholic | 40 | 53 |
| Not very religious (n=140) ^d | 77 | 51 ^e |
| Family experienced prior loss | 77 | 79 |

^aUnivariate analysis. Each parent answered 4 hastening death questions. Percentages correspond to the proportion of parents who endorsed at least 1 hastening death question. P values correspond to univariate logistic regression models in which answers to each hastening death question were considered separate observations, ie, the unit of analysis was each hastening death question. Correlation among responses from the same subject was accounted for using clustered analysis in which level 1 represented the answer to each hastening death question and level 2, each parent.

^bDenominator is indicated when it differs from total sample.

^cIncome was collapsed at US \$75 000, representing the 80th percentile of the US annual household income for the survey years (see "Methods" section).

^dCorresponds to response options "somewhat" and "not at all" religious (vs very religious).

^e $P\leq .01$.

under certain circumstances (**Table 3**). Most commonly, parents would have considered HD if their child had been in uncontrollable pain (34%; 95% CI, 26%-42%). A minority of parents (15% or less) would have considered HD for nonphysical suffering such as not wanting child to live this way, release from life, or to control the death. Almost no parents would have considered HD for circumstances not directly related to the child's experience.

Endorsement of Hastening Death in Vignettes

When responding to the vignettes, 94% of parents (95% CI, 90%-98%) endorsed proportionately intensive symptom management for a terminally ill child with uncontrolled excruciating pain, while only 54% (95% CI, 45%-62%) did so for a child in irreversible coma. Seventy parents (50%; 95% CI, 42%-58%) endorsed HD in at least 1 vignette. Of the 19 parents who reported considering HD during their child's end-of-life course, 16 (84%) also endorsed HD in vignettes. Fifty-nine percent of the parents (95% CI, 50%-67%) would agree with physicians discussing intentionally ending a child's life for a terminally ill child in pain or coma.

Of the family variables analyzed, being white (not Hispanic) and not very religious were associated with endorsement of hastening death in vignettes (**Table 4**). Parents were 40% more likely to endorse hastening death for a child with intractable pain than for a terminally ill child in coma (46% vs 36%; OR, 1.4; 95% CI, 1.1-1.8). Results did not change after adjusting by race and religiousness.

COMMENT

Family perspectives about HD in children have not been previously described. Rather than taking sides in

the HD debate, our intention was to examine this topic from a clinical point of view. Our study reveals that consideration of and discussions about HD in children with cancer do, in fact, occur. We also found that the child's experience of pain affects HD considerations. Specifically, unrelieved pain was associated with parents' past considerations of HD and current views, both regarding their own child and in vignettes. Importantly, parents overwhelmingly endorsed intensive symptom management for pain relief, an alternative approach to relieving uncontrollable pain in children.

More than 1 of every 8 parents reported considering HD and 1 in 10 reported having had an HD discussion, a comparable proportion with what has been described for adults with terminal cancer.⁴ Furthermore, 1 of every 3 parents would have considered HD retrospectively for their own child had the circumstances been different, and 1 of 2 endorsed HD in vignettes, which is also similar to the US public endorsement of HD for adults.¹ These findings suggest that the proportion of parents who would consider HD may fluctuate depending on the child's clinical condition; clinicians caring for a child with advanced cancer should thus be prepared to hold discussions related to HD considerations.

Our findings offer some initial hypotheses regarding underlying factors leading to HD requests. First, suffering may play a role in the family's request. A thorough exploration of the child's suffering from pain as well as other sources may be important. In addition, and not surprisingly, family characteristics are related to parental consideration of HD. Race, religiousness, income, and education have already been identified as characteristics associated with endorsement of HD by the general public.^{24,25} Existing expert recommendations suggest that being sensitive and respectful of these values and having a listening and nonjudgmental attitude may foster an open conversation that increases clinicians' understanding of the family's motivations and, in turn, relieves child and family distress.²⁶ The same experts' guidelines highlight the importance of physicians' self-awareness about their own opinion about HD. In fact, physicians from the Netherlands and Oregon, where HD is legal, report that these conversations are highly challenging. Finding an equilibrium between their position and their willingness to relieve patient suffering does not come easily.^{27,28}

If physical suffering is identified, our results suggest that parents are willing to have an open discussion about existing options including effective and legal alternatives such as proportionately intensive symptom management and palliative sedation. Desires for hastened death may represent an exit plan²⁹ to be used if no other alternatives are recognized. Although we did not explicitly explore this in our sample, the circumstances under which parents would have considered HD for their child suggest that parents may think about HD as a means to end intolerable pain. In these cases, developing alternative plans may ease parent's views about HD. Proportionately intensive symptom management involves, in the case of pain, a proportionate

increase in analgesic doses to control the pain, while accepting a higher risk of sedation or even respiratory depression.³⁰ Palliative sedation (or sedation to unconsciousness) is used in the context of imminent death and may be indicated when all intensive symptom management options fail to provide adequate relief. Palliative sedation involves giving analgesic and sedative agents until unconsciousness is reached and may be accompanied by the withdrawal of life-sustaining treatments to allow death to occur.³¹

When talking to parents about these alternatives, it may be worth explaining that appropriate use of intensive symptom management rarely causes actual hastening of death. Several studies indicate that both caregivers^{32,33} and physicians^{34,35} tend to confuse the unintended adverse effects of intensive symptom management with the intentional hastening of death. In our sample, the 3 families who reported intentionally hastening their child's death described doing so using morphine, which raises the question of whether they had misinterpreted the physicians' intentions. In fact, evidence indicates that opioids can be used safely at the end of life and that their effect on survival, if any, is negligible.³⁶⁻³⁹

The study has some limitations. It could be argued that parental endorsement of HD in hypothetical vignettes may not fully represent their views for a child of their own. However, in this sample, most parents who considered HD during their child's terminal phase also endorsed HD in vignettes. In addition, when asked about circumstances in which they would have considered HD for their own child, parents' answers were similar to those depicted in the vignettes. Specifically, uncontrolled pain was the top factor identified by parents who used both survey strategies. For these reasons, we believe vignettes emerge as a valid and acceptable proxy for current thoughts about HD.

Given our small sample, prevalence estimates may be prone to error. However, in light of the sensitive nature of the topic and social desirability bias, we hypothesize that HD discussions may have been underreported and therefore our results, if anything, would underestimate their frequency. Estimates of HD, on the other hand, may be overestimated given parents' apparent confusion between HD and intensive symptom management. In future studies of determinants of desiring HD, it would also be helpful to include prospective longitudinal data, especially because HD perspectives have been shown to fluctuate over time.⁴⁰

We have only focused on pain as a trigger for HD consideration or discussion; this is clearly a limited view because other types of child or parental suffering may be similarly associated with HD. Although further research is needed to explore these associations, we chose pain because, despite the advances in the palliative care field, this is still a prevalent and inadequately treated symptom.⁴¹

Another limitation is related to the age of the data, which may be of concern for 2 reasons: potential for recall bias and secular trends that influence views about HD. We feel that, given the salience of the event, recall bias about having considered HD is not likely a signifi-

cant concern. Regarding changing secular trends, since the data were collected, 2 states in the US now accept physician-assisted suicide as legal⁶ and, at the same time, palliative strategies are much more integrated into care.⁴¹ It is possible that these changes might affect the prevalence of considering HD, although no recent studies have examined this; on the other hand, the effects of pain on HD views should not be affected by secular trends. Finally, our results are difficult to extrapolate beyond cancer. Other pediatric life-limiting conditions involve varying degrees of disability, burden, and time course, all of which may yield different patterns of HD perspectives among parents.

Our results suggest that more than 1 of every 8 parents report considering HD during their child's illness, and they tended to do so if their child was in pain. In the context of an HD discussion, identifying sources of suffering and clearly explaining effective and legal options, including proportionately intensive symptom management, may ease parents' considerations of hastening their child's death.

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Authors Contributions: Drs Wolfe and Dussel had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. *Study concept and design:* Dussel, Weeks, and Wolfe. *Acquisition of data:* Hilden, Watterson-Schaeffer, and Wolfe. *Analysis and interpretation of data:* Dussel, Joffe, Hilden, Weeks, and Wolfe. *Drafting of the manuscript:* Dussel and Hilden. *Critical revision of the manuscript for important intellectual content:* Dussel, Joffe, Hilden, Watterson-Schaeffer, Weeks, and Wolfe. *Obtained funding:* Wolfe. *Administrative, technical, and material support:* Watterson-Schaeffer. *Study supervision:* Wolfe.

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Announcement

Submissions. The Editors welcome contributions to Picture of the Month. Submissions should describe common problems presenting uncommonly, rather than total zebras. Cases should be of interest to practicing pediatricians, highlighting problems that they are likely to at least occasionally encounter in the office or hospital setting. High-quality clinical images (in either 35-mm slide or electronic format) along with parent or patient permission to use these images must accompany the submission. The entire discussion should comprise no more than 750 words. Articles and photographs accepted for publication will bear the contributor's name. There is no charge for reproduction and printing of color illustrations. For details regarding electronic submission, please see: <http://archpedi.ama-assn.org>.