

Assessing well-being in pediatric palliative care: A pilot study about views of children, parents and health professionals

Original Article

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Abstract

Objectives. Our research aims to compare the perception that children in the pediatric palliative care setting have of their emotional well-being, or that expressed by the parents, with the perception held by the professionals involved in their care.

Methods. In this cross-sectional study, the emotional well-being of 30 children with a mean age of 10.8 years (standard deviation [SD] = 6.1) is evaluated. Children, or parents where necessary, evaluate their situation with a question about emotional well-being on a 0–10 visual analog scale. For each child, a health professional also rates the child's emotional status using the same scale.

Results. The average child's emotional well-being score provided by children or parents was 7.1 (SD = 1.6), while the average score given by health professionals was 5.6 (SD = 1.2). Children or parents graded the children's emotional well-being significantly higher than professionals (t -test = 4.6, p -value < .001). Health professionals rated the children's emotional well-being significantly lower when the disease status was progressive than when the disease was not (t -test = 2.2, p -value = .037).

Significance of results. Children themselves, or their parents, report more positive evaluations of emotional well-being than health professionals. Sociodemographic and disease variables do not seem to have a direct influence on this perception, rather it is more likely that children, parents, and professionals focus on different aspects and that children or parents need to hold on to a more optimistic vision. We must emphasize that when this difference is more pronounced, it can be a warning sign that further analysis is required of the situation.

Introduction

The estimated global total number of children in need of palliative care in 2017 was almost 4 million. Children and adolescents aged 0–19 years make up 7% of the total global palliative care demand. The health conditions that generate the greatest need for palliative care among children are Human immunodeficiency virus/Acquired Immune Deficiency Syndrome, premature birth and birth trauma, congenital anomalies, injuries, malignant neoplasms, and other rare diseases (Connor 2020). The treatment of children with chronic disease is complex and extends over a long period of time (Levine et al. 2021) and, during this period, the child's well-being may fluctuate depending on their state of health, as well as the support received and resources available (Donnelly et al. 2018; Presedo and Wenk 2007).

The literature generally shows that the way children and adolescents experience severe illness is related to adaptive psychological reactions and not to specific clinical or psychopathological disorders (Hernández et al. 2009). This is because patients gradually become more familiar with their situation and, as a result, their maladaptive reactions and symptoms decrease. Suffering is related to emotions, such as fear, anger, sadness, helplessness, and despair (Krikorian and Limonero 2012). Most young people with life-threatening illnesses often experience symptoms of anxiety and depression, which are especially common in adolescents (Weaver et al. 2016), as well as nervousness or irritability (Collins et al. 2002), while the most prevalent mental health problems are adaptive and behavioral disorders, and post-traumatic stress, together with depression and anxiety (DeJong and Fombonne 2006; Krikorian and Limonero 2012). It is particularly difficult for children to differentiate psychological symptoms from their actual physical symptoms (Woodgate et al. 2003).

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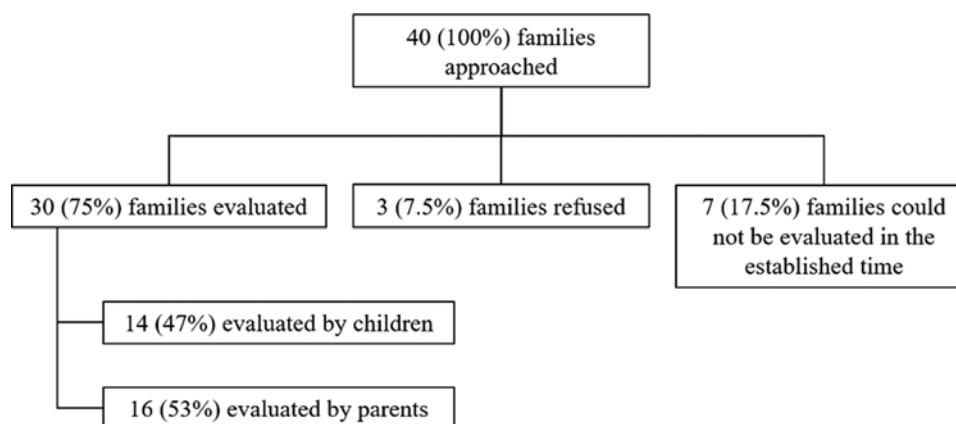


Fig. 1. Flow chart of participants in the evaluation of well-being in the palliative pediatric unit.

In clinical practice, treatment decisions are often, at least partly, based upon quality-of-life considerations. Therefore, it is important to be aware of differences in the perception of emotional well-being expressed by children, physicians, and parents (Janse et al. 2008). In the pediatric setting, to assess the well-being of children and adolescents, the perspective of different informants is crucial. The children's own perception of their well-being should be noted whenever possible, but when they cannot communicate, information provided by parents, who know their children better than anyone, can help toward making an assessment. In addition, health-care professionals who work closely with patients (Barry et al. 2013; Mash and Hunsley 2010; Whitcomb and Merrell 2013) are also key informants. In palliative pediatric care, children's developmental stages (biological maturation) or their capacity for verbal communication, resulting from their cognitive development or neurological deterioration caused by the disease itself (Bogetz and Lemmon 2021; Wood et al. 2010), may make interpretation of a child's emotional sphere even more complicated than it already is in adults.

However, clinically relevant discrepancies are known to exist between the reports of parents and children, and those of the practitioners (Janse et al. 2008). Some studies compared perceptions of quality of life among children, parents, and physicians and showed the objective attributes had higher percentage agreement between children/parents and physicians than the subjective attributes, like emotion and well-being (Janse et al. 2004). In the case of a pediatric cancer patient, parents are known to be more optimistic about their child's prognosis and that the physician's assessment tends to be less so (Levine et al. 2021). Other studies indicate that successful symptom treatment may not be the only crucial variable influencing main outcome measures, such as satisfaction with care, quality of life of children and parents, or peacefulness of the dying phase. Concordant symptom perception between parents and professionals appears to be a pivotal factor in predicting both satisfaction with the care team and parental quality of life (Vollenbroich et al. 2016).

Our research aims to compare the perception that children in the pediatric palliative care setting have of their emotional well-being, or that expressed by the parents of those children who cannot communicate, with the perception held by the professionals involved in their care. Our hypothesis is that there will be differences between the perception expressed by the children and their parents, compared to that expressed by health-care professionals.

Methods

Study design

This is a cross-sectional study of the perception of the emotional well-being of children nearing the end of their life.

Settings

In this study, we used a convenience sample of children being treated at the Pediatric Palliative Care Unit (PPCU) of the Sant Joan de Déu Hospital (Barcelona, Spain). We evaluated the perception of well-being of all the children through assessments, attempting to gauge the opinions of the children (themselves if they had verbal communication or, if not, of their parents) and health-care professionals.

Participants

The inclusion criteria were as follows: (a) children with a life-threatening or life-limiting illness, (b) the child's first multidisciplinary evaluation had been carried out by the PPCU, (c) the father and/or mother were the child's legal tutors, and (d) both had signed the consent form.

Variables and data collection

Senior psychologists from the palliative care service collected data via interviews with the participating children or parents and health-care professionals (doctors and nurses from the PPCU). To obtain the evaluation of the well-being of children, the researchers created 2 groups: children or parents and professionals. The group of children or parents was made up of the children themselves when they could answer according to their evolutionary stage or the parents of the children if the child was under 8 years of age or had severe neurological impairment that did not allow him/her to answer. According to the literature (Feeny et al. 1998), children of 7 years and older can answer questions regarding their own health. The group of professionals was made up of pediatricians and/or nurses from the PPCU who were referents for that child and family.

Sociodemographic information on the participating children was obtained, such as age, gender, whether they had any siblings, national origin, family cohabitation, and school attendance.

Illness data collected included diagnosis, clinical situation, and length of time they had been visiting the PPCU.

Perception of emotional well-being

To collect data on the perception of emotional well-being of the children, we used an adaptation to Distress Thermometer (DT) (Graham-Wisener et al. 2021; Mitchell et al. 2011) which is a one-item instrument indicating a patient's general distress level on a 0–10 visual analog scale. The DT (0 for no distress; 10 for extreme distress), developed by the National Comprehensive Cancer Network panel, was used within their guidelines for the management of emotional distress. In our research, children were asked: "Over the last few days, in general, how have you been feeling? Ranging from 0 to 10, where 0 corresponds to very bad and 10 to very good." For parents and professionals, the question was adapted as follows: "Over the last few days, how would you assess the well-being of your/this child?" The score ranges from 0 (very bad) to 10 (very good). The lower the scores, the worse the emotional state. This question is adapted from the "Detection of Emotional Distress (DED) scale" (Limonero et al. 2012, 148; Maté et al. 2009, 517) which measures the emotional distress of patients and end-of-life situations. Once the child's well-being was initially assessed, the health workers were asked for their evaluations within a 3-day period to ensure that the time difference did not result in a confounding variable, thus avoiding potential sources of bias.

Statistical methods

Data analysis was carried out using the software program *R Core Team v.4.2.1*. Descriptive means and standard deviations (SDs) were calculated. The *t*-test and *F*-statistic for the variance of the group means were carried out, along with one-sided tests for paired samples and nonparametric Wilcoxon–Mann–Whitney tests.

Results

Figure 1 is a flow chart representing the participants in the study. Of the 40 families who were approached to participate in the study, 3 (7.5%) refused to participate and 7 children (17.5%) could not be assessed in the evaluation window. Of the 30 children in the final sample, 14 children were themselves able to express their level of well-being, while that of the other 16 was expressed by parents since those children could not communicate. All children were assessed by a health professional.

The mean age of children was 10.8 years (SD = 6.1; range: $0 < \text{age} < 21$), 11 were females (37%), and 19 were males (63%). In total, 12 children (40%) attended school (Table 1). Oncohematological diseases were present in 53.3% of the cases and neurological disease in 36.7%. The clinical situation was stable for 20 of the children (66.7%) and in progression for 10 children (33.4%). On average, children had been treated in the palliative care unit for 7.8 months (SD = 12.6) at the time of the interview.

A two-sided *t*-test for mean differences is used to compare the differences between the "children or parents" group and the "health professionals" group when they rate children's emotional well-being (Table 2). The results reveal that there is no statistically significant difference in the mean scores of males vs. females, nor in the children's or the parents' evaluations ($p = .979$) or in the health professionals' assessments ($p = .373$). No difference is found by groups of children or parents in any of the comparisons by informants, by speciality (oncology or neurology), age group, schooling, siblings and cohabitation condition, origin, or time visiting the PPCU.

Table 1. Sociodemographic and clinical characteristics of the children ($N = 30$)

Characteristics	<i>N</i> (%)
Sociodemographic data	
Age	
Mean (SD)	10.83 (6.13)
Gender	
Male	19 (63)
Female	11 (37)
Origin	
Spain	21 (70)
Others	9 (30)
School attendance	
Yes	12 (40)
No	18 (60)
Family cohabitation	
With both parents	21 (70)
Separated parents	7 (23)
Single parent	2 (7)
Siblings	
Yes	23 (77)
No	7 (23)
Clinics	
Informant	
Parent	16 (53)
Child	14 (47)
Kind of disease	
Oncohematological	16 (53)
Neurological and others	11 (37)
Other	3 (10)
Clinical Situation	
Stable	20 (67)
Progressing	10 (33)
Months in unit	
Mean (SD)	7.8 (12.7)

Health professionals rated well-being when the disease status was in progression (mean = 5.1, SD = 1.1) significantly ($p = .037$) lower than when the disease was stable (mean = 6.2, SD = 1.4).

The scores provided by children or parents (mean = 7.1, SD = 1.6) and their corresponding paired health professionals (mean = 5.8, SD = 1.4) indicate that children or parents provide higher scores (means and SDs are shown in Table 2). In order to see if the difference made in the evaluation of the children well-being between "children or parents" and "professionals" is maintained considering the different sociodemographic and clinical variables, Table 3 shows the difference between the mean score given by children or parents minus the mean score given by health professionals. The one-sided *t*-test for the difference in means for

Table 2. Emotional well-being evaluation of children ($N = 30$) by informants

		<i>N</i>	Children or parents		Professionals	
			<i>M</i> (SD)	<i>p</i> *	<i>M</i> (SD)	<i>p</i> *
Sociodemographic data						
All patients		30	7.125 (1.577)	–	5.800 (1.381)	–
Age	≤10 years	15	7.467 (1.827)	.243	5.767 (1.400)	.898
	>10 years	15	6.783 (1.250)		5.833 (1.410)	
Gender	Male	19	7.118 (1.385)	.979	5.605 (1.162)	.373
	Female	11	7.136 (1.938)		6.136 (1.704)	
Origin	Spain	21	7.190 (1.553)	.748	5.667 (1.399)	.429
	Others	9	6.972 (1.716)		6.111 (1.364)	
School attendance	Yes	12	7.042 (1.712)	.822	5.583 (1.443)	.499
	No	18	7.181 (1.529)		5.944 (1.360)	
Family cohabitation	Both parents	21	7.286 (1.765)	.303	5.738 (1.463)	.697
	Others	9	6.750 (1.000)		5.944 (1.236)	
Siblings	Yes	23	7.293 (1.375)	.428	5.826 (1.474)	.833
	No	7	6.571 (2.149)		5.714 (1.113)	
Clinics						
Informant	Child	14	7.268 (1.521)	.649	5.857 (1.574)	.839
	Parent	16	7.000 (1.663)		5.750 (1.238)	
Illness	Oncology	16	7.172 (1.540)	.326	6.000 (1.517)	.521
	Neurology	11	6.636 (1.551)	**	5.273 (1.104)	**
	Others	3	8.667 (1.155)		6.667 (1.155)	
Clinical situation	Stable	20	7.438 (1.332)	.185	6.150 (1.387)	.037
	Progressing	10	6.500 (1.900)		5.100 (1.125)	
Time visiting PPCU	≤6 months	19	7.276 (1.361)	.542	5.789 (1.357)	.959
	>6 months	11	6.864 (1.938)		5.818 (1.488)	

**p*-value: two-sided *t*-test of the mean difference between the 2 groups evaluated by the same informant.

***p*-value: two-sided *F*-test of the mean difference between several groups evaluated by the same informant.

paired samples reveals a mean assessment of “children or parents” higher than that of professionals (difference = 1.3, *t*-test = 4.6, $p < 0.001$).

Similarly, a significantly higher difference in the average score is obtained for professionals compared to children or parents independently of who is assessing the child. When children evaluate their own status (mean = 7.3, SD = 1.5), their rate is higher than that of their corresponding health professional (mean = 5.9, SD = 1.6). The one-sided *t*-test for paired samples indicates that the difference is significant (difference = 1.4, *t*-test = 3.1, $p = .004$). When parents evaluate their child (mean = 7.0, SD = 1.7), their rate is also higher than that of the health professionals evaluating their child (mean = 5.7, SD = 1.2), and the one-sided test again indicates that the score is higher (difference = 1.3, *t*-test = 3.3, $p = .003$).

Higher average scores of children or parents compared to health professionals are found independently of the disease status ($p < .001$ when the disease status is stable, and $p = .012$ when the disease status is in progression), for children aged 10 years or under ($p = .001$) or more than 10 years ($p = .008$), for those attending

school ($p = .012$) and for those that do not attend school ($p < .001$), and by medical speciality ($p = .009$ for oncology and $p = .002$ for neurology). No difference is found in the mean score of well-being provided by children or parents and professionals for medical specialities other than oncology and neurology, although there are only 3 children in this group. Similarly, no evidence is found for children of origins other than Spanish ($p = .085$) and children with no siblings ($p = .086$), but again these are small groups with fewer than 10 children.

When assessing children by sex, the mean score provided by male children (mean = 7.1, SD = 1.4) and their corresponding health professionals (mean = 5.6, SD = 1.2) is higher (*t*-test = 4.7, $p < .001$). A significantly higher score cannot be detected (*t*-test = 1.8, $p = .052$) when comparing female children (mean = 7.1, SD = 1.9) and their corresponding health professionals (mean = 6.1, SD = 1.7).

Figure 2 presents the individual paired evaluations provided by children or parents (left) and the health professionals (right) together with a box-plot. In 20 cases, the connecting dashed line is seen to fall, indicating that the evaluation made by children or

Table 3. Differences in well-being mean scores of children or parents minus health professional rating

		<i>N</i>	Difference	<i>t</i> -test	<i>p</i> **
Sociodemographic data					
All patients		30	1.325	4.593	<.001
Age	≤10 years	15	1.700	3.783	.001
	>10 years	15	.950	2.712	.008
Gender	Male	19	1.513	4.660	<.001
	Female	11	1.000	1.786	.052
Origin	Spain	21	1.524	4.593	<.001
	Others	9	.861	1.511	.085
School attendance	Yes	12	1.458	2.625	.012
	No	18	1.236	3.864	<.001
Family cohabitation	Both parents	21	1.548	4.510	<.001
	Others	9	.806	1.549	.080
Siblings	Yes	23	1.467	4.352	<.001
	No	7	0.857	1.549	.086
Clinics					
Informant	Child	14	1.411	3.142	.004
	Parent	16	1.250	3.250	.003
Illness	Oncology	16	1.172	2.632	.009
	Neurology	11	1.364	3.687	.002
	Others	3	2.000	1.732	.113
Clinical situation	Stable	20	1.288	3.626	<.001
	Progressing	10	1.400	2.689	.012
Time visiting PPCU	≤6 months	19	1.487	4.085	<.001
	>6 months	11	1.045	2.162	.028

***p*-value: paired sample one-sided test of the mean difference between children's or parents' and professional's evaluation.

parents is higher than that made by health professionals (and in 6 cases, the difference is by more than 2 points). There is no difference in the score provided by children or parents and their health professional in 7 specific cases; only in 3 cases, did children or parents feel worse than the health professionals' assessment.

Figure 3 presents the individual differences of the emotional well-being scores provided by children or parents and their corresponding health professional, ordered from highest to lowest. Where the child has provided a self-assessment, the bar is shaded in a dark color, and where the parents have provided the emotional assessment, the bar is shown in a lighter color. The figure does not show a systematically higher difference between children and professionals compared to the difference between parents and professionals.

Discussion

Our study highlights that there is a different assessment of emotional well-being between the children (children themselves or their parents) and the health professionals who treat them, usually with a more positive assessment being made by children or parents.

For the group of children or parents, no differences were found in the evaluation of emotional well-being in relation to sociodemographic and clinical variables. In other studies that compare the prognostic vision of patients and professionals, a significant difference was found among patients in different diagnostic groups (Levine et al. 2021). In the study of Wolfe et al. (2015), which evaluated symptoms in the last 12 weeks of life of 25 children and adolescents (with ages ranging from 7 to 18 years old), symptoms were reported along with a high degree of emotional well-being, with physical symptoms being particularly frequent in the final weeks of life. This is not observed in the evaluations of our children or parents, which prompts us to question how much of their discomfort is based on the clinical situation of the disease and how much is due more to psychosocial problems or anticipation of future scenarios, as other studies point out (Baggott et al. 2014). In our research, we have not compared the perception of well-being that children express with that expressed by their own parents, but it is important to highlight that the evidence points to significant differences. Parents reported a higher prevalence of physical and psychological symptoms than children for every symptom except shortness of breath. The overestimation of symptom prevalence was most significant for the physical symptoms of fatigue, nausea, and lack of appetite and for the psychological symptoms of feeling nervous and sadness (Baggott et al. 2014; Montgomery et al. 2020). Although including the child's perspective is an essential component of understanding the individual experience of suffering, and thus of improving overall care during advanced stages of an illness, it is a perspective that is often overlooked (Montgomery et al. 2016; Wolfe et al. 2015). The group of professionals tended to evaluate the well-being of the child differently, depending on whether the child's clinical situation was progressive or stable, something that did not occur in the children or parents group. Health professionals when assessing a clinical situation of an illness in progression tended to perceive the children as having a worse emotional state. Clinicians may be more influenced by, and in turn more focused on, the course of the disease when assessing a child's well-being.

In line with the main objective of the study, significant differences were found between the evaluation of children's emotional well-being made by children or parents and that of health professionals. Children or parents always value children's emotional well-being more positively than do the professionals. Even if differentiating between the group of children or parents of responding children and that of responding parents, the differences remain. Our findings are consistent with the study of Wolfe et al. (2000) who described a staggering difference between the parents' and the health-care providers' perception of symptoms during the dying phase, and that this might contribute to the child's suffering. In our study, parents really appreciated appropriate communication in advance about possible distressing symptoms that might arise during the last days of their child's life (Vollenbroich et al. 2016). Others studies found that parent-provider agreement regarding prognosis and goals of therapy was generally poor. Overall, parents tended to be more optimistic than providers (Levine et al. 2021; Rosenberg et al. 2014). One possible explanation is that parents give a higher score to emotional well-being and socialization, while health professionals focus on evaluating objective components (the attributes of vision, hearing, speech, ambulation, or dexterity) related to the quality of life (Janse et al. 2008; Morrow et al. 2008). Family members are often managing the conflicting emotions of not wanting their child to suffer but not wanting their child to die and have to adapt rapidly and repeatedly to new situations. Coping

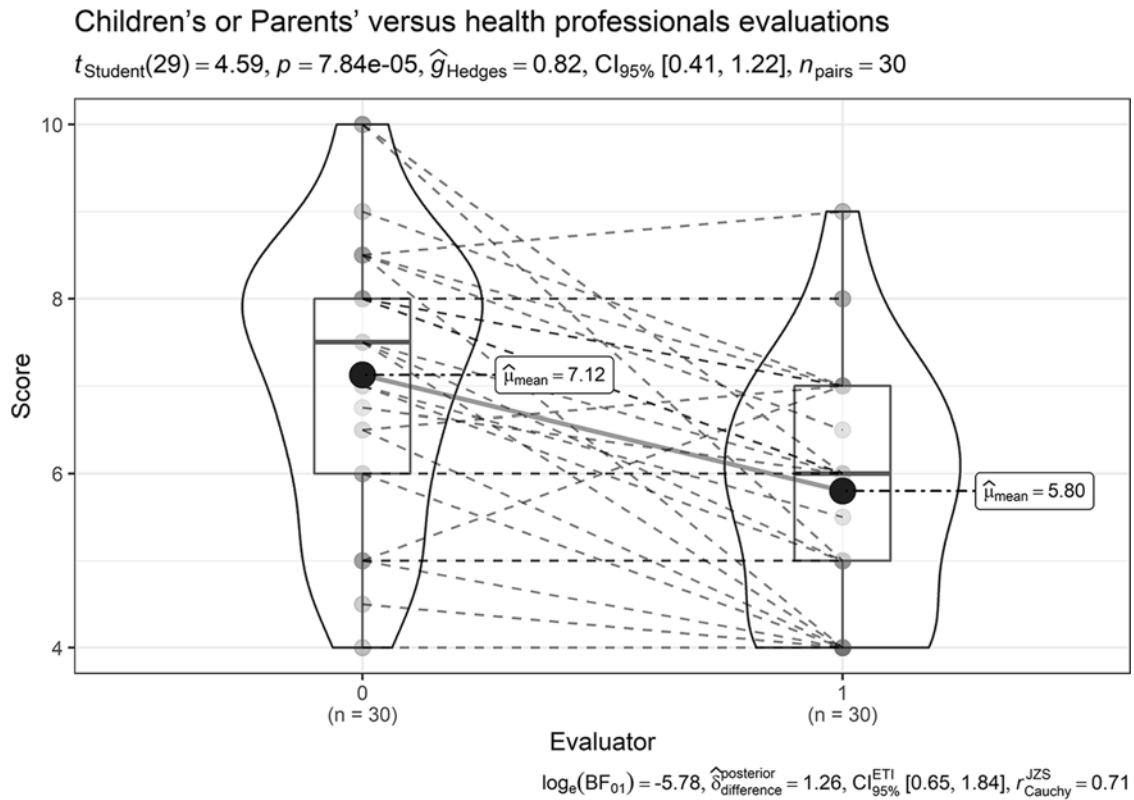


Fig. 2. Paired scores in the well-being assessment (N=30).

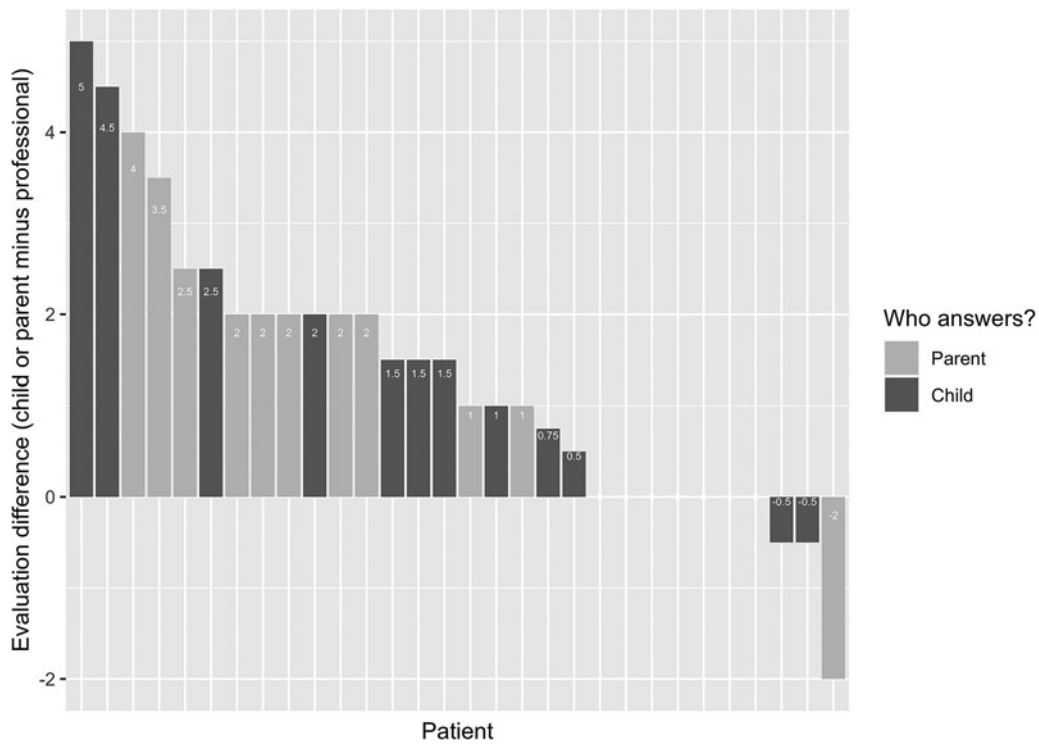


Fig. 3. Individual differences of the emotional well-being scores.

strategies include trying to maintain hope and “staying positive” (Mitchell et al. 2022).

The findings of this study may have important clinical implications. First, it points to the need for health professionals to ensure

there is effective communication with children and their parents. Clinicians should remember that even moderate levels of discord could potentially lead to disagreements, misunderstandings, and loss of trust if children or parents feel their concerns are not being

addressed by the clinical team (Hill *et al.* 2017). Some studies suggest that optimism may be conveyed directly from the physician through overly optimistic statements or that optimism may be implied through the avoidance of difficult discussions (Levine *et al.* 2021). Although some clinicians may be reticent in sharing realistic information for fear of taking away hope, honest disclosure of a poor prognosis may in fact foster hope (Mack *et al.* 2007) by allowing families to make the best decision possible for their child's care. In contrast, excessive optimism from the physician or lack of sharing of information can threaten hope and harm the parent-physician relationship, since parents often depend on their physician for direct information and guidance in decision-making (Nyborn *et al.* 2016).

Second, we must remember that optimism is a coping strategy that can be temporarily adaptive for children and their parents. From the results obtained in our study and those already presented by other studies which also compare the perception of children, parents, and professionals, clinicians must bear in mind that these differences in perception do not have to lead to a discrepancy in the emotional well-being of the child, but rather to the use of scale or words. It could be that children and parents, armed with optimism as a coping strategy, find it difficult to negatively evaluate their well-being and that it is easier for professionals to give low scores. There is also a possibility that participants may have expressed prognostic optimism as a function of performative language, maintaining a positive mindset to influence a preferred outcome (Levine *et al.* 2021). This also leads us to consider the importance of using this type of scale as a comparative measure for the same subject at different times, and not to compare between subjects. Recognizing this tendency toward optimism in patients and families may enable clinicians to guide communication and aid in decision-making, supporting hope but also clearly communicating facts and realistic probabilities. Hope is essential for people who are coping with serious and prolonged psychological stress, and it is not a perpetually self-renewing resource; it has peaks and troughs and, at times, can be absent altogether (Folkman 2010). Without a proper understanding of the variation in the parental sense of duty, professionals may be inadequately prepared to understand parents' decisions and help them prioritize their duties based on an accurate prognosis (Feudtner *et al.* 2015).

Third, detecting extreme cases in these discrepancies, either too high or too low, is crucial. In the case that the difference is negative, that is, children or parents value their well-being more negatively than the professionals, this could be a signal indicating that the child is experiencing greater suffering and requires further attention. On the contrary, extreme cases of optimism may lead to nonadaptive coping styles and could result in the child's suffering being underplayed. An excessive optimism may impair the ability of families to make informed care decisions throughout the disease trajectory (Levine *et al.* 2021).

Finally, for a global evaluation of the well-being or emotional state of a child or adolescent at the end of their life, it is essential to consider both the assessment given by the child, or possibly their parents, and the health professionals (Montgomery *et al.* 2020). It should be remembered that the professionals, and to a certain extent the parents, are observers and base their evaluations on both a rational and emotional judgment of what they think may be affecting the child (Limonero *et al.* 2016; Stein *et al.* 2019; Vollenbroich *et al.* 2016). Thus, we cannot ignore the fact that in pediatric palliative care, health-care professionals are exposed to emotionally demanding clinical experiences with high levels of bonding and involvement when the suffering of a child or family

is particularly intense (Kase *et al.* 2019), and this could also lead to the overestimation of psychosocial concerns. As we have seen, health-care professionals tend to evaluate emotional well-being more negatively than the parents and the children themselves. Interestingly, a better evaluation given by children or parents compared to that given by their health professional might be a sign of good caring standards.

Conclusions

Despite the difficulties inherent in advanced and end-of-life disease in the pediatric population, children with communication skills can assess their own level of emotional well-being, while the assessment of children without verbal communication relies on evaluations made by their parents. Compared to the assessment made by children or parents, the health professionals provide a significantly lower score. That difference exists even if we consider age groups (children less than 10 years old and children aged 10 years or over), illness status (stable or in progression), type of disease, and school attendance. Differences persist independently of whether the children themselves provided a self-assessment, or whether the assessment was carried out by the parents.

The triad of informants (children, parents, and professionals) must be seen and treated as complementary in order to establish the best possible evaluation of the children's emotional well-being, especially when the child lacks verbal communication skills.

When dual assessments are made by children or parents and health professionals simultaneously, those children or parents who report an emotional well-being score lower than the assessment made of them by their health professional should be carefully monitored. A lower score on children's or parents' side may be a sign of distress that requires further analysis in case additional emotional support is needed.

Limitations and future research

Despite the importance of the findings reported here, this study has several limitations that merit consideration. The first has to do with the use of a convenience sample of children with advanced or end-stage illnesses being treated at a palliative care unit. The second limitation is related to the sample size. Studies are needed that include more children, relatives, and professionals, albeit acknowledging the inherent difficulty of the end-of-life situation in pediatric patients. The third is related to the assessment of emotional well-being for children unable to communicate orally, for which the study relied on the parents' assessment. Finally, the scale used in the study was designed for adult populations. Specific tools could be developed for the pediatric population, and instruments to assess patients' well-being could be designed for PPCU health professionals. Likewise, our study had a cross-sectional design. To confirm these results, it would be appropriate to carry out longitudinal studies with the participation of a greater number of health centers to avoid evaluative biases of health professionals.

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References

- Baggott C, Cooper BA, Marina N, et al.** (2014) Symptom assessment in pediatric oncology: How should concordance between children's and parents' reports be evaluated? *Cancer Nursing* 37(4), 252–262. doi:10.1097/NCC.000000000000111
- Barry CT, Frick PJ and Kamphaus RW** (2013) Psychological assessment in child mental health settings. In Geisinger KF (ed), *APA Handbook of Testing and Assessment in Psychology, Vol. 2: Testing and Assessment in Clinical and Counseling Psychology*. Washington, DC: American Psychological Association, 253–270.
- Bogetz JF and Lemmon ME** (2021) Pediatric palliative care for children with severe neurological impairment and their families. *Journal of Pain and Symptom Management* 62(3), 662–667. doi:10.1016/j.jpainsymman.2021.01.008
- Collins JJ, Devine TD, Dick GS, et al.** (2002) The measurement of symptoms in young children with cancer: The validation of the Memorial Symptom Assessment Scale in children aged 7–12. *Journal of Pain and Symptom Management* 23(1), 10–16. doi:10.1016/S0885-3924(01)00375-X
- Connor SR** (ed) (2020) *Global Atlas of Palliative Care at the End-of-Life*. London, UK: Worldwide Palliative Care Alliance and World Health Organization.
- DeJong M and Fombonne E** (2006) Depression in paediatric cancer: An overview. *Psycho-Oncology* 15(7), 553–566. doi:10.1002/pon.1002
- Donnelly JP, Downing K, Cloen J, et al.** (2018) Development and assessment of a measure of parent and child needs in pediatric palliative care. *Journal of Pain and Symptom Management* 55(4), 1077–1084. doi:10.1016/j.jpainsymman.2017.12.484
- Feeny D, Juniper EF, Ferrie P, et al.** (1998) Why not just ask the kids? Health-related quality of life in children with asthma. In Drotar D (ed), *Measuring Health-Related Quality of Life in Children and Adolescents Implications for Research and Practice*. Mahwah, NJ: Lawrence Erlbaum Associates Publishers, 171–185.
- Feudtner C, Walter JK, Faerber JA, et al.** (2015) Good-parent beliefs of parents of seriously ill children. *JAMA Pediatrics* 169(1), 39. doi:10.1001/jamapediatrics.2014.2341
- Folkman S** (2010) Stress, coping, and hope. *Psycho-Oncology* 19(9), 901–908. doi:10.1002/pon.1836
- Graham-Wisener L, Dempster M, Sadler A, et al.** (2021) Validation of the Distress Thermometer in patients with advanced cancer receiving specialist palliative care in a hospice setting. *Palliative Medicine* 35(1), 120–129. doi:10.1177/0269216320954339
- Hernández S, López C, and Durá E** (2009) Indicadores de alteraciones emocionales y conductuales en menores oncológicos [Indicators of emotional and behavioral disorders in children with cancer]. *Psicooncología* 6(2–3), 311–325.
- Hill DL, Nathanson PG, Fenderson RM, et al.** (2017) Parental concordance regarding problems and hopes for seriously ill children: A two-year cohort study. *Journal of Pain and Symptom Management* 53(5), 911–918. doi:10.1016/j.jpainsymman.2016.11.007
- Janse AJ, Gemke RJB, Uiterwaal CSPM, et al.** (2004) Quality of life: Patients and doctors don't always agree: A meta-analysis. *Journal of Clinical Epidemiology* 57(7), 653–661. doi:10.1016/j.jclinepi.2003.11.013
- Janse AJ, Sinnema G, Uiterwaal CSPM, et al.** (2008) Quality of life in chronic illness: Children, parents and paediatricians have different, but stable perceptions. *Acta Paediatrica* 97(8), 1118–1124. doi:10.1111/j.1651-2227.2008.00847.x
- Kase SM, Waldman ED and Weintraub AS** (2019) A cross-sectional pilot study of compassion fatigue, burnout, and compassion satisfaction in pediatric palliative care providers in the United States. *Palliative & Supportive Care* 17(3), 269–275. doi:10.1017/S1478951517001237
- Krikorian A and Limonero JT** (2012) An integrated view of suffering in palliative care. *Journal of Palliative Care* 28(1), 41–49. doi:10.1177/082585971202800107
- Levine DR, CuvIELLO A, Nelson C, et al.** (2021) Hope-colored glasses: Perceptions of prognosis among pediatric oncology patients and their parents. *JCO Oncology Practice* 17(6), e730–e739. doi:10.1200/OP.20.00762
- Limonero JT, Maté J, Mateo D, et al.** (2016) Desarrollo de la escala DME-C: Una escala para la detección del malestar emocional de los cuidadores principales de personas con enfermedad avanzada o al final de la vida [Development of the DME-C scale: A scale for the detection of emotional distress in the main caregivers of people with advanced disease or at the end of life]. *Ansiedad Y Estrés* 22(2–3), 104–109. doi:10.1016/j.anyes.2016.09.001
- Limonero JT, Mateo D, Maté-Méndez J, et al.** (2012) Evaluación de las propiedades psicométricas del cuestionario de Detección de Malestar Emocional (DME) en pacientes oncológicos [Evaluation of the psychometric properties of the Emotional Discomfort Detection Questionnaire (DME) in cancer patients]. *Gaceta Sanitaria* 26(2), 145–152. doi:10.1016/j.gaceta.2011.07.016
- Mack JW, Wolfe J, Cook EF, et al.** (2007) Hope and prognostic disclosure. *Journal of Clinical Oncology* 25(35), 5636–5642. doi:10.1200/JCO.2007.12.6110
- Mash EJ and Hunsley J** (2010) Evidence-based assessment of child and adolescent disorders: Issues and challenges. *Journal of Clinical Child & Adolescent Psychology* 34(3), 362–379. doi:10.1207/s15374424jccp3403_1
- Maté J, Mateo D, Bayés R, et al.** (2009) Elaboración y propuesta de un instrumento para la detección del malestar emocional en enfermos al final de la vida [Development and proposal of an instrument for the detection of emotional distress in patients at the end of life]. *Psicooncología* 6, 507–518.
- Mitchell AJ, Hussain N, Grainger L, et al.** (2011) Identification of patient-reported distress by clinical nurse specialists in routine oncology practice: A multicentre UK study. *Psycho-Oncology* 20(10), 1076–1083. doi:10.1002/pon.1815
- Mitchell S, Slowther A-M, Coad J, et al.** (2022) Facilitators and barriers to the delivery of palliative care to children with life-limiting and life-threatening conditions: A qualitative study of the experiences and perceptions of healthcare professionals. *Archives of Disease in Childhood* 107(1), 59–64. doi:10.1136/archdischild-2021-321808
- Montgomery K, Sawin KJ and Hendricks-Ferguson VL** (2016) Experiences of pediatric oncology patients and their parents at end of life: A systematic review. *Journal of Pediatric Oncology Nursing* 33(2), 85–104. doi:10.1177/1043454215589715
- Montgomery KE, Vos K, Raybin JL, et al.** (2020) Comparison of child self-report and parent proxy-report of symptoms: Results from a longitudinal symptom assessment study of children with advanced cancer. *Journal for Specialists in Pediatric Nursing*, 26, e12316. doi:10.1111/jspn.12316
- Morrow AM, Quine S, Loughlin EVO, et al.** (2008) Different priorities: A comparison of parents' and health professionals' perceptions of quality of life in quadriplegic cerebral palsy. *Archives of Disease in Childhood* 93(2), 119–125. doi:10.1136/adc.2006.115055
- Nyborn JA, Olcese M, Nickerson T, et al.** (2016) "Don't try to cover the sky with your hands": Parents' experiences with prognosis communication about their children with advanced cancer. *Journal of Palliative Medicine* 19(6), 626–631. doi:10.1089/jpm.2015.0472
- Presedo A and Wenk R** (2007) IMPaCCT: Standards for paediatric palliative care in Europe. *European Journal of Palliative Care* 14(3), 109–114. doi:10.1007/s00482-008-0690-4
- Rosenberg AR, Orellana L, Kang TI, et al.** (2014) Differences in parent-provider concordance regarding prognosis and goals of care among children with advanced cancer. *Journal of Clinical Oncology* 32(27), 3005–3011. doi:10.1200/JCO.2014.55.4659
- Stein A, Dalton L, Rapa E, et al.** (2019) Communication with children and adolescents about the diagnosis of their own life-threatening condition. *The Lancet* 393(10176), 1150–1163. doi:10.1016/S0140-6736(18)33201-X
- Vollenbroich R, Borasio GD, Duroux A, et al.** (2016) Listening to parents: The role of symptom perception in pediatric palliative home care. *Palliative & Supportive Care* 14(1), 13–19. doi:10.1017/S1478951515000462

- Weaver MS, Heinze KE, Bell CJ, et al.** (2016) Establishing psychosocial palliative care standards for children and adolescents with cancer and their families: An integrative review. *Palliative Medicine* **30**(3), 212–223. doi:10.1177/0269216315583446
- Whitcomb SA, and Merrell KW** (2013) *Behavioral, Social, and Emotional Assessment of Children and Adolescents*. New York: Routledge/Taylor & Francis Group.
- Wolfe J, Grier HE, Klar N, et al.** (2000) Symptoms and suffering at the end of life in children with cancer. *The New England Journal of Medicine* **342**(5), 326–333. doi:10.1056/NEJM200002033420506
- Wolfe J, Orellana L, Ullrich C, et al.** (2015) Symptoms and distress in children with advanced cancer: Prospective patient-reported outcomes from the PediQUEST study. *Journal of Clinical Oncology* **33**(17), 1928–1935. doi:10.1200/JCO.2014.59.1222
- Woodgate RL, Degner LF and Yanofsky R** (2003) A different perspective to approaching cancer symptoms in children. *Journal of Pain and Symptom Management* **26**(3), 800–817. doi:10.1016/S0885-3924(03)00285-9
- Wood F, Simpson S, Barnes E, et al.** (2010) Disease trajectories and ACT/RCPC categories in paediatric palliative care. *Palliative Medicine* **24**(8), 796–806. doi:10.1177/0269216310376555