The needs of children with life-limiting conditions: A healthcare-provider–based model

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Abstract

Pediatric hospice and palliative care has progressed in recent years with the development of new programs and models of care. Missing from the empirical literature, however, is a model of the needs of children. The purpose of the present study was to develop an empirically based conceptual model of the needs of children with life-limiting conditions. Recognizing the value of both qualitative and quantitative data, concept mapping methodology was selected as an effective way to obtain data that reflected both the "big picture" and subtleties of pediatric end-of-life needs. The seven-cluster concept map appeared best in terms of both interpretability and parsimony. This model includes the following clusters of needs: 1) pain, 2) decision making, 3) medical system access and quality, 4) dignity and respect, 5) family-oriented care, 6) spirituality, and 7) psychosocial issues. We believe that the development of a comprehensive model of the needs of such children is a step toward concrete, measurable, and effective support for children and their families.

Key words: pediatrics, palliative care, needs, concept mapping

Introduction

The field of pediatric hospice and palliative care has progressed rapidly in recent years, particularly in generation of new program initiatives and models of care.[1-5] Perhaps the most important current issue is the development of an evidence base to guide policy and practice.[6] Feudtner and colleagues[7] made a major contribution to this effort with their study of complex chronic conditions, charting national trends in the characteristics of terminally ill children.[7] This study helped to define the US population in terms of the numbers of children affected in various diagnostic groups and pointed toward the importance of the identification and assessment of their specific supportive care needs.

Conducting such needs assessments presupposes that a paradigm or model of needs exists. Yet, a review of the literature indicates that no such work has been published. A search of Medline using the terms "needs" and "health service needs and demands" produced a total of 93,163 hits. Limiting the citation set to children in the age range zero to 18 reduced the number of references to 19,149. When

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the citation set was combined with the key words "palliative care" or "hospice care" (along with all subheadings), the number of citations was reduced to 93, seven of which were not relevant to a pediatric population. In the final set of 86 papers, there were no studies that attempted to provide a comprehensive, empirically based model of the needs of children or families of children with life-limiting illnesses. In the small number of empirically based studies, there were several important contributions to the understanding of specific kinds of needs (see, for example, the recent work on spiritual needs by Feudtner et al.[8] and Davies et al.[9]). Overall, however, the literature related to the assessment of the needs of children in palliative and hospice care to this point can be characterized as largely qualitative and narrowly focused.

This situation is similar to the one that existed in the adult hospice and palliative care literature until recently. Recognizing the importance of a model of needs for theory and practice, Emanuel and colleagues[10] set out to develop a model of the needs of adult patients in end-of-life (EOL) care as both a conceptual framework and the basis of measure development. The resulting instrument, The Needs at the End-of-Life Screening Tool (NEST), was the result of a carefully planned, multistep effort that included conceptual and measurement studies. The NEST conceptual model is a very useful summary of EOL needs in terms of education as well as program planning and evaluation. The measurement model includes both a short clinical screening measure and a more detailed instrument useful for research.

The purpose of the present study was to develop an empirically based conceptual model of the needs of children with life-limiting conditions. Recognizing the value of both qualitative and quantitative data, we chose the concept mapping methodology as an effective way to obtain data that reflected both the "big picture" and subtleties of pediatric EOL needs. Briefly, concept mapping is a systematic approach to tapping the shared expertise of a group by constructing statistically based graphic models of the areas examined by the group. There are typically six steps in the process, which have been described in detail by Trochim.[11-13] Concept mapping is based on multidimensional scaling and cluster analysis, thus providing a more rigorous statistical basis for modeling needs than focus groups or other strictly qualitative methods. The statistical procedures guide the analyst in producing the most valid and reliable representation of the data. Human judgment is not removed from the process, however, and is critical in the cluster analysis and the interpretation of the resulting maps. The Web-based approach to concept mapping is a relatively new innovation and has been used in recent health-related studies (e.g., Trochim et al.[14]).

Context of the present study

This study was conducted as part of a federally funded demonstration project developed and administered by Children's Hospice International (CHI). New York was one of five states initially funded to study and stimulate new models of pediatric palliative care. The specific purpose of all of the demonstration projects has been to further the development of CHI's Program for All-Inclusive Care for Children and Their Families (CHI PACC®). A general summary of the demonstration project in New York was included in a recent Institute of Medicine (IOM) report.[15] The NY project included the development of a statewide advisory committee of experts in pediatric palliative care. The advisory committee included all of the authors of this article and was the organizational base for conduct of this study.

Methods

Participants

The study included two levels of sampling designed to tap as comprehensive a set of experts as possible within the sampling frame of NY State. The first level was the NY State Advisory Committee on Pediatric Hospice and Palliative Care. The committee was organized under the leadership of the Hospice and Palliative Care Association of NY State. At the time of the study, the membership of the committee included 25 professionals with expertise in pediatric palliative and hospice care. The professions represented on the committee included nursing (n = 6), social work (n = 6), public health (n = 4), medicine (n = 4), psychology (n = 3), education (n = 1), and pastoral care (n = 1). The committee members were asked to invite colleagues with similar experience and expertise to participate. These invitations were standardized to include a brief introduction to the study, data collection procedures and informed consent, and a link to the study site. This second level of sampling resulted in an additional 25 expert participants.

Procedures

Brainstorming on children's needs. The first phase of the study was accomplished by the use of a Web page set up to solicit input regarding the needs of children with life-limiting illness. The site was designed with input from the study team and maintained by Concept Systems, Inc. (Ithaca, NY) on a secure server. Brainstorming was conducted over a one-month period based on a focus statement, as follows: "Generate statements that describe the needs of children with life-limiting illness." Advisory committee members were sent weekly email reminders about participation in the study. This process produced 134 need statements, which were then edited for redundancy and clarity. The final set of statements included 74 items.

Sorting and rating the needs statements. The next step in concept mapping entails sorting the statements so the perceived similarity of the items can be statistically modeled. The standard sorting procedures developed by Trochim[11] were followed in this study. The statements were entered into a database on the Concept Systems server, and new Web pages were constructed. A panel of 12 of the advisory committee members sorted the 74 items into groups of similar items on the new Web pages. They were instructed to log on to the site and first complete a free sort of the items. The sorting was to be done so that items were grouped by similarity "in any way that makes sense to you," except that items could neither be in one large group or 74 individual piles.

Following the sorting, all the committee members as well as the additional expert colleagues were asked to rate each item as to relative importance and the feasibility of meeting the specific need given current resources and policies. The importance of each need was rated on a 1 to 5 scale in which 1 represented "relatively unimportant" and 5 represented "extremely important." The feasibility ratings also ranged from 1 to 5, with 1 representing "not feasible" and 5 representing "already being done." The advisory group was invited to participate in this phase of the project and again asked to invite colleagues as in the prior brainstorming phase. A total of 32 experts contributed ratings of importance and feasibility of the individual needs. The raters included nurses (n = 7), social workers (n = 7), physicians (n = 6), public health administrators (n = 4), psychologists (n = 3), educators (n = 2), and pastoral care providers (n = 3). It is possible that a smaller number participated in this phase than the brainstorming because more time was required to complete the ratings than to add to the brainstormed needs items. Weekly reminders were e-mailed to the advisory committee members over the month-long ratings phase.

Data analysis

Concept mapping involves two major statistical analyses: multidimensional scaling (MDS), and cluster analysis. Trochim's original paper[11] provides a detailed review of these methods and the ways that they are integrated in concept mapping. The essential goal of the analysis was first to develop a statistical map of the individual brainstormed items based on the degree of similarity in how they were sorted by the individual participants. The next goal was to identify the most representative structure of the map via the analysis of how the items were grouped (in the cluster analysis). Concept mapping has been compared to astronomy in the sense that the items can be seen to represent the stars and the clusters to represent the constellations. Concept mapping analysis attempts to first identify the arrangement of the items in two dimensional space and then to identify the concepts represented in the clustered items.

In this study, our first step was to submit the sorted responses to a two-dimensional nonmetric MDS analysis. The Concept Systems program aggregated each individual's sorted items into a binary, symmetric matrix. Every pair of statements in the matrix was either coded as 1 if the statements were sorted together or 0 if they were not. The MDS analysis produced a two-dimensional representation of all of the statements based on the degree of similarity of each item to all other items as indicated by the sorting. An X-Y value for each statement defined its position on the map, with items closer to one another representing more similar constructs and those further apart reflecting less similar ideas.

The MDS results were then examined in a hierarchical cluster analysis. The cluster analysis, based on Ward's algorithm,[16] involved an iterative process in which each possible solution from 20 to three clusters was examined for interpretability and statistical indicators of adequacy of the solution. The statistical indicator of interest is the "bridging value," an index ranging from 0 to 1 that indicates the degree to which an item was frequently sorted within a particular cluster versus being placed in other clusters by different participants. High bridging values for a cluster suggest the possibility of a more complex construct that might be better represented in more differentiated clusters, thus encouraging the analyst to continue disaggregating the data into smaller clusters. As is suggested by the term "concept map," this technique employed graphic representation in the interpretation of the data. Three kinds of maps are typically examined in order: 1) the point map (in which each item is shown by number in two dimensional space); 2) the cluster map (which adds cluster boundaries around the items that define each cluster); and 3) the cluster rating map (in which the item ratings are overlaid on the cluster map, in this case showing the relative importance and feasibility of each cluster).

The maps were reviewed and interpreted by the study team and by the NY State advisory committee with feedback from conference participants at annual meetings of the NY State Hospice and Palliative Care Association and CHI and from the editors of the IOM text on improving pediatric palliative care.[6]

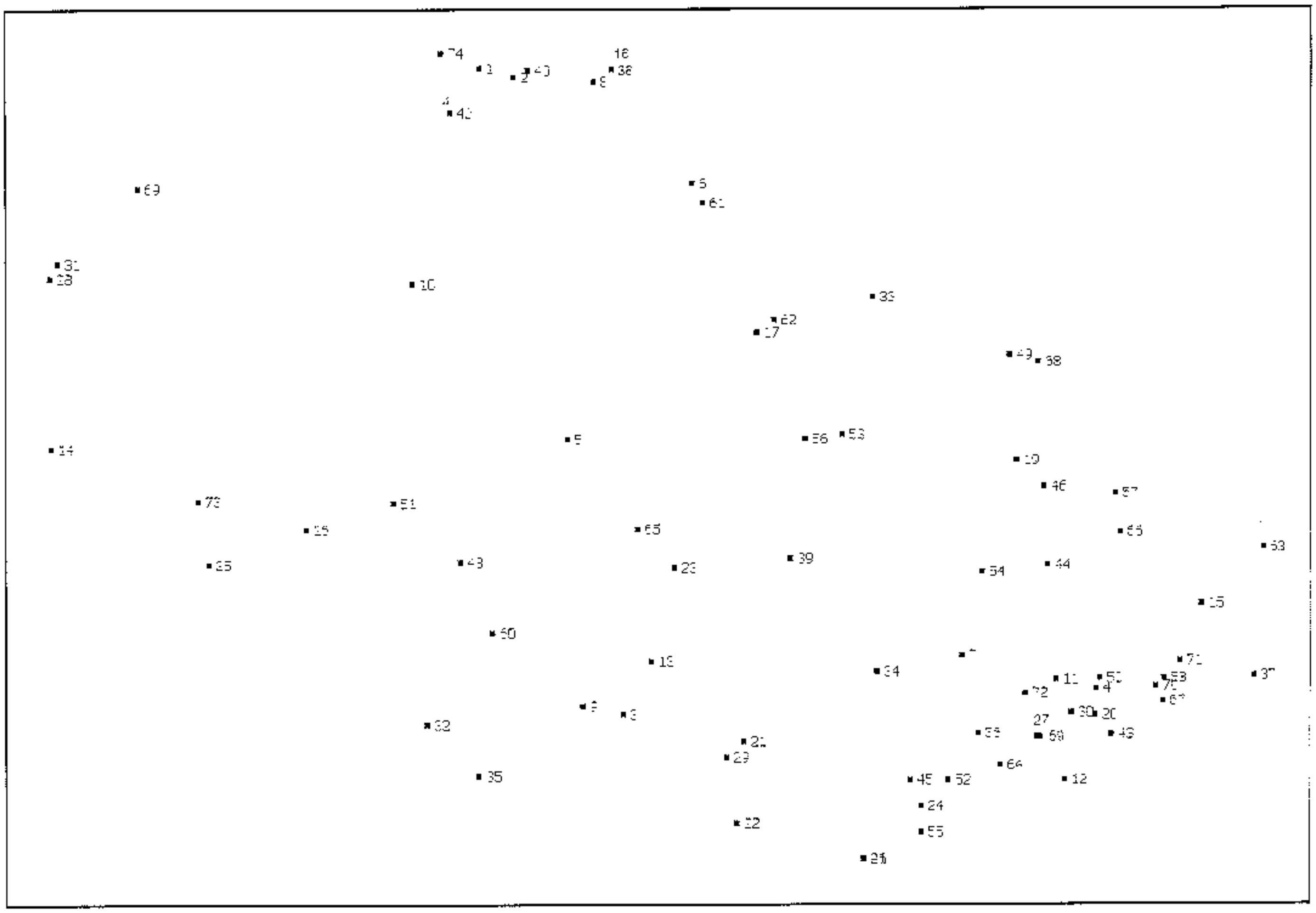

Figure 1. Point map of multidimensional scaling of the 74 needs statements.

Results

The MDS analysis of the perceived similarity of the needs statements produced a stress value (a goodness of fit statistic) of .213 after 14 iterations, lower (i.e., better) than the reference value of .285 reported by Trochim[14] based on the average of 33 studies (range, 0.155 to 0.352). Figure 1 is the point map showing the MDS arrangement of the 74 items. Items that were sorted together more frequently appear closer to each other on the map, and items that were perceived to be dissimilar are farther apart.

The cluster analysis included examination of all possible maps from two to 20 clusters. Cluster interpretation shows increasing differentiation from smaller

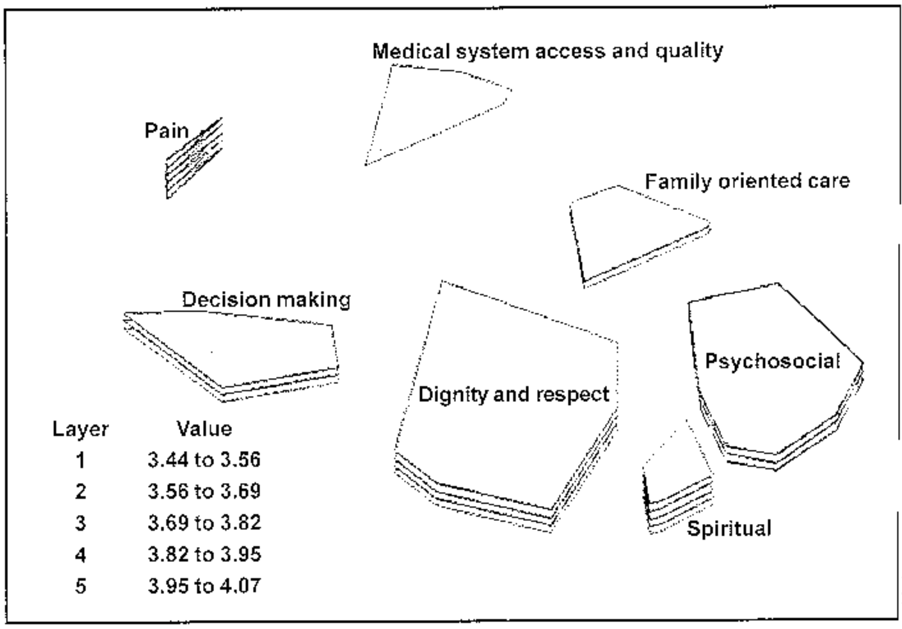

Figure 2. Seven-cluster concept map with feasibility ratings.

Table 1. Statement numbers, statements within clusters, and importance and feasibility rating by cluster importance mean

Number	Statement	Importance	Feasibility
Pain		**4.90**	**4.07**
28)	Effective pain management	5.00	4.22
31)	Consistent pain assessment	5.00	4.11
69)	Accurate assessment and effective treatment of pain and nonpain symptoms	4.70	3.89
Decision making		**4.30**	**3.81**
14)	Clear, developmentally appropriate explanations of care options, benefits, and burdens	4.50	3.78
51)	The right to say no	4.50	3.89
73)	To have a say in the treatment plan	4.50	4.00
48)	Assessment of personal goals of care	4.30	3.89
25)	Understandable information re: palliative/hospice care to reduce anxiety	4.10	3.89
16)	Assessment of perceptions of burdens and benefits of care	3.90	3.44
Medical system access and quality		**4.14**	**3.44**
10)	Comforting atmosphere with pain control	4.90	3.67
74)	Reduction of barriers imposed by limits on the hospice benefit	4.70	3.00
1)	Access to palliative care from the time of diagnosis without a time constraint	4.60	3.44
47)	Competent pediatric-trained professional caregivers	4.30	3.67
2)	Coordinated healthcare provided in a timely, convenient, and pleasant environment	4.20	3.56
6)	Consistency in professional caregivers throughout the illness, including the end stage	4.20	3.11
8)	Not spending hours and hours in clinics and waiting rooms	4.10	3.22
40)	The ability to transition in or out of the hospital as needed	4.00	3.89
18)	Being able to give home blood transfusions, especially platelets	3.80	3.22
42)	More nurses/HHAs who are pediatric-trained	3.80	3.00
61)	Nutritional support in the home	3.70	4.22
38)	Ability for NP/MDs to make home visits	3.40	3.22
Dignity and respect		**4.14**	**3.93**
32)	Quality of life	4.90	3.78
3)	Honesty	4.60	4.00
29)	To maintain a sense of self	4.50	4.00
60)	Comfort	4.50	4.22
9)	To be clearly valued as an individual by having preferences solicited and acted upon	4.40	3.67
21)	Sense of control over life or some aspects of it	4.30	3.78
65)	Confidentiality	4.20	4.11
5)	Developmentally appropriate activities and information	4.10	4.22
34)	Access to peers	4.10	3.78
39)	Privacy	4.10	4.00
35)	To be physically touched and soothed (e.g., massage)	3.90	4.33
13)	Assessment and facilitation of preferences/goals for social interaction	3.60	4.00
23)	Culturally sensitive care	3.60	3.44
22)	Self-relaxation skills	3.20	3.67
Family-oriented care		**4.11**	**3.67**
53)	Family-focused care	4.40	4.00

Table 1. Statement numbers, statements within clusters, and importance and feasibility rating by cluster importance mean (continued)

Number	Statement	Importance	Feasibility
49)	As much time at home as possible (as little time in the hospital)	4.30	3.67
33)	Flexibility to receive care wherever it is safe	4.20	3.67
68)	Being able to remain in familiar surroundings with familiar people	4.20	3.67
17)	Translators if the child's first language is not English	4.10	3.56
62)	Care for the healthcare provider (so that they can be caring and nurturing)	3.90	3.44
56)	Alternative therapies such as art and music	3.70	3.67
Spiritual		**4.11**	**3.98**
26)	Prayers	4.70	4.78
24)	To be reassured that he or she is important and will be remembered	4.60	4.22
52)	Knowing he or she won't be forgotten and will still be loved after death	4.30	3.89
41)	Spirituality in their care plans	4.10	4.00
45)	Focus on the child's hopes/dreams (even when they are likely not to be met)	4.10	3.67
36)	To acknowledge sadness of the child and loved ones about illness and possibility of death	4.00	4.11
27)	Pleasant distractions from the situation	3.90	4.00
64)	To create a personal legacy	3.70	3.44
55)	Assessment and support of concerns around meaning, loss, and spiritual issues	3.60	3.67
Psychosocial		**3.96**	**3.75**
43)	Love	4.70	4.78
15)	Opportunities to be cared for by loving family	4.40	4.22
19)	Unlimited access to family as desired by the child	4.40	3.67
20)	Fun	4.40	4.00
63)	Parents who are mentally healthy and functional under stress	4.30	3.33
7)	To address fears with a competent professional	4.20	3.89
11)	Talk about their feelings and fears	4.20	3.89
71)	Continuity of "normal life" within their family, school, faith/social community	4.20	3.22
37)	Parent support so that they can focus on the child and siblings as much as possible	4.10	3.78
46)	Child life intervention in the home	4.10	3.56
66)	To have the critical nature of the illness and possibility of death acknowledged	4.00	3.56
30)	Stimulation (via school activity, play, family activities, etc.)	3.90	4.00
67)	Regular contact with peers	3.90	3.56
4)	Laughter for release	3.80	3.78
12)	Nonjudgmental love, touch, long talks, looking out a window, feeling the sun	3.80	4.00
58)	To not feel that the child has caused other losses for the family (e.g., financial)	3.80	3.78
59)	People, things, and activities that make the child smile and laugh	3.80	3.89
54)	Play therapy that focuses on illness-related topics	3.70	3.89
44)	Peer support groups	3.60	3.44
70)	Ability to share with children having same illness in a safe, encouraging environment	3.60	3.56
72)	Help with visible effects of illness (body image/self-esteem)	3.60	3.56
50)	Networking with other children experiencing a similar illness, treatment, etc.	3.50	3.44
7)	Access to child-friendly Web sites for information, chats, etc.	3.10	3.89

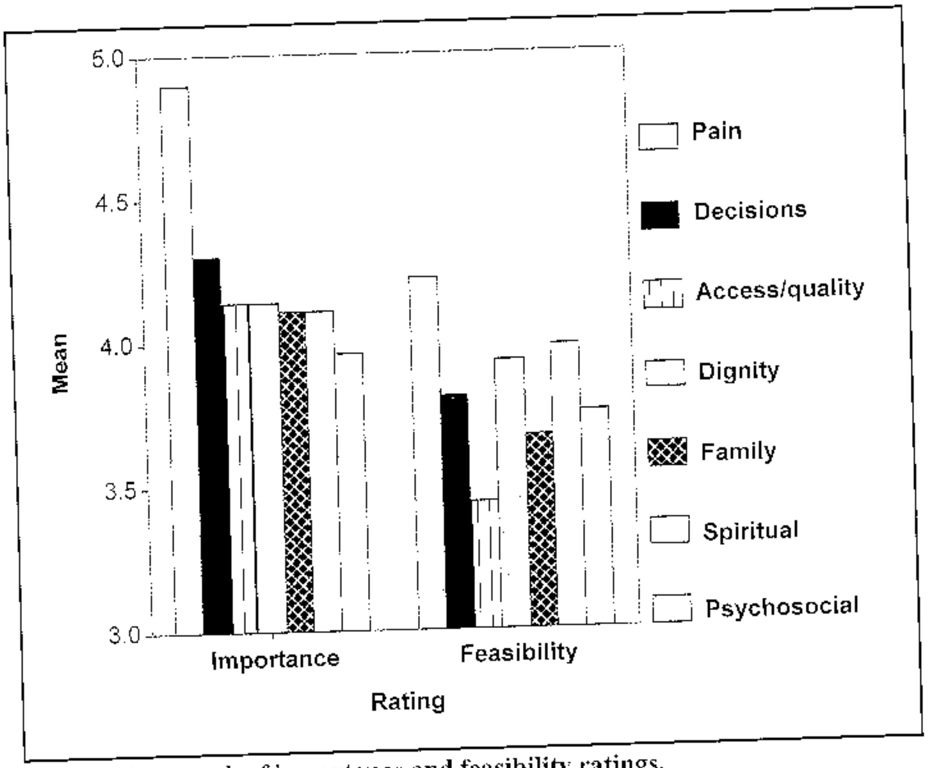

Figure 3. Bar graph of importance and feasibility ratings.

to larger numbers of clusters but decreasing internal coherence and substantive importance of the concept in the cluster.[21] The seven-cluster solution appeared best in terms of both interpretability and parsimony. This model includes the following clusters of needs: 1) pain, 2) decision making, 3) medical system access and quality, 4) dignity and respect, 5) family-oriented care, 6) spirituality, and 7) psychosocial issues. The concept map with the cluster labels is presented in Figure 2.

Dignity and respect form the most central cluster in the concept map. The cluster includes such needs as quality of life, honesty, maintaining a sense of self, being valued as an individual by having preferences solicited and acted upon, privacy, confidentiality, and culturally sensitive care. The relatively central location of the cluster is also significant because it indicates that this cluster is the one that is most closely related to all other clusters. Thus, the centrality of the dignity and respect cluster may suggest not only that these are core needs of children but also that these needs are closely related to all other areas of need for children with life-limiting illnesses. This finding suggests that dignity and respect should receive explicit attention in pediatric palliative-care program planning and evaluation.

The left side of the map appears to include mainly needs that are specific to the medical context, while the right side appears to reflect more personal needs. For example, pain control for children with life-limiting illness is widely acknowledged as a primary goal of supportive care and is represented in the concept map by a three-item cluster. In our study, more than one-third of the needs statements generated by the experts reflect psychosocial functioning. The items included a number of universal needs that all children (healthy or not) have, such as love, access to peers, and fun. The majority of statements were specific to children with life-limiting illness such as to be reassured that he or she is important and will be remembered and pleasant distractions from the situation.

A spirituality cluster was identified between the psychosocial and dignity-and- respect clusters. The items in the spirituality cluster included prayers and spirituality as a part of care as well as items that might be classified as more existential than spiritual. There is also a cluster of needs related to maintenance of family functioning including home-based child-life services and sibling support. Several of the items reflected the need for the child to have access to his or her family when hospitalized and for as much care as possible to be delivered in the home. Decision making, one of the most stressful aspects of EOL care at any age, was also represented in a separate cluster.

It was not surprising to find that one of the clusters of the needs assessment involved access to quality medical care. Among the items were those related to access policies (access to the palliative care benefit from the time of diagnosis without a time constraint) and more programmatic issues such as ability for nurse practitioners or doctors to make home visits, ability to transition in and out of the hospital as needed, and competent pediatric-trained professional caregivers. Thus, new programs should consider system factors in terms of who will have access under what circumstances and what services shall be delivered in which settings, as well as how to assure competency of professional caregivers.

Importance and feasibility ratings

The complete list of children's needs along with the importance and feasibility ratings is presented in Table 1. The needs statements are listed within the clusters identified in the previous section, and these clusters are sorted by the mean importance rating per cluster. The pain cluster was the smallest in terms of number of items, but was rated most important (mean = 4.90). The two items with the highest importance ratings of all 74 items were "effective pain management" and "consistent pain assessment" (the average rating for both items was the maximum value of 5 indicating "most important"). The psychosocial cluster included the largest number of items (23), but had the lowest mean importance of the seven clusters (mean = 3.96). It should be noted that the range of the importance ratings was limited. Specifically, the difference between the most and least importantly rated cluster was about 1 scale point. Thus, none of the needs identified should be considered unimportant, but some may be seen as relatively less important than others.

Figure 3 presents a bar graph of the importance and feasibility cluster. This graph clearly shows that, for many of these clusters, a discrepancy between attributions of importance and feasibility exists. It is encouraging that pain is regarded highly not only in importance but also in terms of feasibility; pain management is recognized to be important and also something for which effective techniques exist. The discrepancy between the importance and feasibility ratings is greatest in the medical-system access and quality cluster—an acknowledgement of the fact that changing systems is easier said than done.

Discussion

The present study is the first to attempt to develop a comprehensive, empirically based model of the needs of children in palliative and hospice care. The study is also a first step in what aspires to be a program of research modeled on prior work with the adult population.[17-20] Similar to this prior work, our study of needs of children includes dimensions at several system levels (individual, family, and care system) and the potential to provide other benefits in research and care. These benefits include development of measures of needs, development of specific and sensitive programs and program evaluations guided by insight about needs, and improved quality of life for children and their families.

Development of a measure of needs of children may have great utility in clinical care planning and evaluation. For example, a common palliative-care program entry point for children with cancer is at the point of relapse. Assessment of the child's needs at this point is currently a common but not standardized practice. The present model will, following a validation study with children and families, provide the basis for a psychometric instrument that can be used in clinical and research applications. Ultimately, national databases built on standardized measures offer the best long-term hope for systematic evidence-based improvements in care for children with complex chronic conditions at the end of life.

An empirically based model of the needs of a population is an important first step in efforts to define the kind of services to be included in a program as well as a basis for evaluating those services. Pediatric palliative programs that employ the concept map presented here will have some guidance in decision making as resources are committed and goal achievements measured. However, a strong degree of confidence in the validity of this model will only be possible with input from patients and family members and from a broader sample of experts. We will seek this input in order to both refine the individual items and to see if the structure of the model can be replicated with new data.

In addition, we are currently conducting a case synthesis of all available case studies of children at end of life to examine the content validity of the model. We have identified approximately 50 published cases. In this analysis, each case is being coded for the presence or absence of the items presented herein and also for the presence of any needs not identified in our concept mapping study.

The feasibility and importance ratings, while based on a relatively small sample of experts, also point to some troubling disconnects in what is perceived to be important and what is perceived to be feasible. The largest discrepancy in the ratings of importance and feasibility occurred in the medical system access and quality cluster. Improving the lot of children with life-limiting conditions will require advocacy as well as continued contributions to the evidence base of pediatric medicine. Help for children and families must be demonstrably effective, but more basically, must be accessible.

Maslow's hierarchy of human needs continues to be the subject of debate in terms of its structural validity,[21-23] but it has also continued to inspire investigations in fields from health to organizational behavior.[24-25] The present study is only a beginning step toward a common model of pediatric palliative care needs, and replication, especially with the consumers themselves (children and their families), is required before the benefits of a common approach will be seen. However, the field is relatively young, and debate about the structure, content, and best methods of meeting needs of children and families is very much to be desired.

There is no question that enhancing quality of life is the goal of palliative care. The present model of needs may be seen as a step in this direction to the extent that the seven domains are validated in future research. Ultimately, the definition of quality of life for children with life-limiting conditions is a personal one for the individual child and the family. We believe that the development of a comprehensive model of the needs of such children is a step toward concrete, measurable, and effective support.

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References

1. Armstrong-Dailey A, Zarbock S: *Hospice Care for Children* (2nd ed.). London: Oxford University Press, 2001.
2. Frager G: Pediatric palliative care: Building the model, bridging the gaps. *J Palliat Care.* 1996; 12(3): 9-12.
3. Levetown M: New programs for children living with life-threatening conditions. *Texas Med.* 2001; 97(8): 60-63.
4. Himelstein BP, Hilden JM, Boldt AM, et al.: Pediatric palliative care. *N Engl J Med.* 2004; 350(17): 1752-1762.
5. Kane JR, Primomo M: Alleviating the suffering of seriously ill children. *Am J Hosp Palliat Care.* 2001; 18(3): 161-169.
6. Field MJ, Behrman RE: *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families.* Washington, DC: National Academies Press, 2003.
7. Feudtner C, Hays RM, Haynes G, et al.: Deaths attributed to pediatric complex chronic conditions: National trends and implications for supportive care services. *Pediatrics.* 2001; 107(6): E99.
8. Feudtner C, Haney J, Dimmers MA: Spiritual care needs of hospitalized children and their families: A national survey of pastoral care providers' perceptions. *Pediatrics.* 2003; 111(1): E67-72.
9. Davies B, Brenner P, Orloff S, et al.: Addressing spirituality in pediatric hospice and palliative care. *J Palliat Care.* 2002; 18(1): 59-67.
10. Emanuel LL, Alpert HR, Emanuel EE: Concise screening questions for clinical assessments of terminal care: The needs near the end-of-life care screening tool. *J Palliat Med.* 2001; 4(4): 465-474.
11. Trochim WM: An introduction to concept mapping for planning and evaluation. *Eval Program Plan.* 1989; 12(1): 1-16.
12. Trochim WM: Concept mapping: Soft science or hard art? *Eval Program Plan.* 1989; 12(1): 87-110.
13. Trochim WM, Linton R: Conceptualization for planning and evaluation. *Eval Program Plan.* 1986; 9(4): 289-308.
14. Trochim WMK, Stillman FA, Clark PI, et al.: Development of a model of the tobacco industry's interference with tobacco control programmes. *Tob Control.* 2003; 12(2): 140-147.
15. Donnelly JP, Huff, SH, Lindsey ML, et al.: Progress in pediatric palliative care in New York State: A demonstration project. In Behrman MFR (ed.): *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families.* Washington, DC: National Academies Press, 2003: pp. 638-664.
16. Everitt B: *Cluster Analysis.* New York: Halsted Press, 1980.
17. Emanuel LL, von Gunten CF, Ferris FD: Advance care planning. *Arch Fam Med.* 2000; 9(10): 1181-1187.
18. Emanuel LL, von Gunten CF, et al.: Gaps in end-of-life care. *Arch Family Med.* 2000; 9(10): 1176-1180.
19. Martin DK, Emanuel LL, Singer PA: Planning for the end of life. *Lancet.* 2000; 356(9242): 1672-1676.
20. Emanuel EJ, Fairclough DL, Slutsman J, et al.: Assistance from family members, friends, paid caregivers, and volunteers in the care of terminally ill patients. *N Engl J Med.* 1999; 341(13): 956-963.
21. Soper B, Milford GE, Rosenthal GT: Belief when evidence does not support theory. *Psychol Marketing.* 1995; 12(5): 415-422.
22. Kiel JM: Reshaping Maslow's hierarchy of needs to reflect today's educational and managerial philosophies. *J Instruct Psychol.* 1999; 26(3): 167-168.
23. Hagerty MR: Testing Maslow's hierarchy of needs: National quality-of-life across time. *Soc Indicators Res.* 1999; 46(3): 249-271.
24. Benson SG, Dundis SP: Understanding and motivating health care employees: Integrating Maslow's hierarchy of needs, training and technology. *J Nurs Manage.* 2003; 11(5): 315-320.
25. Harper FD, Harper JA, Stills AB: Counseling children in crisis based on Maslow's hierarchy of basic needs. *Int J Advance Counselling.* 2003; 25(1): 10-25.
26. Bolen RM, Lamb J, Gradante J: The Needs-Based Assessment of Parental (Guardian) Support: A test of its validity and reliability. *Child Abuse Neglect.* 2002; 26(10): 1081-1099.