Running Title: Health Services Utilization for Children With Complex Chronic Conditions
Running Author: Pérez-Ardanaz et al.
Original Manuscript

Socioeconomic Status and Health Services Utilization for Children With Complex Chronic Conditions Liable to Receive Nurse-Led Services: A Cross-Sectional Study

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Abstract

Aim

To analyze the use of health services for children with severe chronic diseases, seeking to identify patterns of use according to sociodemographic and clinical conditions, and to identify unmet needs of care coordination that could benefit from nursing case management services.

Design

Cross-sectional study.

Methods

Children treated in ambulatory and hospital care in Granada, Spain, with complex chronic diseases in 2016 were analyzed to determine their use of healthcare resources. Socioeconomic variables were evaluated, along with clinical status and duration of their conditions.

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Results

In total, 265 children were analyzed (mean age 7.3 years, *SD* 4.63; 56.6% male). The average duration of the disease was 63.26 months (*SD* 54.09). The most common types of disease were neurological (35.80%), congenital (23.90%), and oncological (18.90%). Multivariate analysis showed that children in need of advanced care ($\beta = 0.71$), with a relatively recent diagnosis ($\beta = -0.11$), with criteria for palliative care 1 ($\beta = -0.26$), and whose mothers were older ($\beta = 0.36$) and had a higher educational level ($\beta = 0.19$) made greater use of healthcare resources during the preceding 12 months, whether urgent or scheduled ($r^2 = 78.0\%$, $p < .001$).

Conclusions

Children with higher needs for advanced care have a heterogeneous use of healthcare resources depending on certain clinical and sociodemographic determinants. This finding has important implications for care coordination and in the identification of profiles of children and families needing significant healthcare resources that could not be accessed in a timely manner to manage their condition.

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Clinical Relevance

A significant proportion of the children used multiple health services, being treated at several centers simultaneously, and producing up to 139 total yearly contacts with the health system. Policymakers, healthcare providers, and patients' families should engage in a redesign of healthcare services for these children, providing comprehensive and coordinated systems of care for this population.

Accepted: 24 March 2018

Keywords

Case management
child health services
chronic disease
healthcare disparities
hospice and palliative care nursing
multimorbidity
pediatric nursing
socioeconomic factors

With the increasing effectiveness of health services, together with sociodemographic and epidemiological changes, analysts are witnessing a rising prevalence of chronic, degenerative, and oncological diseases among children around the world (American Academy of Pediatrics, 2013; Cohen, Jovcevska, Kuo, & Mahant, 2011). Such processes, in children with complex or incurable diseases, or life-threatening or limiting conditions, provoke the need for frequent hospitalizations, consultations, and tests (Cook & Rocker, 2014; Ogelby & Goldstein, 2014; Walter, DeCamp, Warrier, Murphy, & Keefer, 2013), and constitute a major challenge to health authorities in many countries (EAPC Taskforce for Palliative Care in Children, 2009).

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However, this challenge cannot be addressed by taking the traditional curative approach towards acute processes. Instead, health services must be reoriented to provide comprehensive, person-centered caring that includes not only treatment of the disease, but also the management of symptoms, promotion of self-care, and attention to outcomes that are important to the patient (such as quality of life, relief of symptoms, and maintaining the patient's dignity in the final phases of life; Moore & Sheetz, 2014). Pediatric palliative care (PPC) is needed in many of these situations, although there is great variability in the provision of these services. In this process, decision making should be shared, facilitating uninterrupted transfer of care and ensuring that it is provided according to the family's wishes until the end of life (Feudtner et al., 2011; Groh, Feddersen, Führer, & Borasio, 2014; Kaye et al., 2015; World Health Organization, 2014).

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Children with health complexities and special needs, such as palliative care, usually have family-identified healthcare service needs and present with functional limitations that may require complex devices and assistance at home, together with considerable use of health resources (hospitalization, multiple health providers, etc.). These children and their parents often have to manage interactions with numerous medical specialists and related health consultations

(Cohen, Kuo, et al., 2011). In addition, they are more likely to receive delayed care and to experience unmet care and coordination needs (Nageswaran, Silver, & Stein, 2008). Furthermore, there may be socioeconomic disparities in the provision of health care for children with complex healthcare needs, which has an immediate impact on their quality of life (Didsbury et al., 2016; Johnston et al., 2017).

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Some models of integrated care for children have been proposed to provide holistic care of children and their families in these complex scenarios (Looman et al., 2013; National Association of Pediatric Nurse Practitioners, 2009). Many of these models have an advanced practice nurse or a case manager nurse as a key provider to guarantee appropriate care coordination. Their approach encompasses clinical care, patient and family education, coordination of health services, and identification and referral to appropriate community resources (Institute of Medicine, 2011). These nursing services are not always available; case finding criteria have been not developed; these services do not take into account social determinants; or, in the worst cases, care integration with different providers is not present (Hudon et al., 2017).

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Methods

The aim of this study was to examine the use made of health services by children with advanced chronic conditions, to identify patterns of use in relation to sociodemographic and clinical conditions, and to identify unmet needs of care coordination that could benefit from nursing case management services.

Design

A cross-sectional study was performed of children with advanced chronic conditions who required palliative care according to the criteria of the Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT) and the Royal College of Paediatrics and Child Heath (EAPC Taskforce for Palliative Care in Children, 2007).

Participants

The study was conducted at the Virgen de las Nieves Hospital complex in Granada (southern Spain), which is part of the public national health system. This is a reference center for ambulatory and hospital palliative care for the population in Granada under 18 years of age (170,808 inhabitants). In 2015, the hospital provided 66,382 pediatric consultations and treated 14,336 children, of whom 42 later died (Observatorio de la Infancia en Andalucía, 2016).

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The population considered for inclusion in the study were all the children under 18 years of age who had life-threatening complex chronic conditions (LT-CCCs) and were treated at the hospital in 2016. The parents of the children were approached and their consent to participate was requested, after ensuring there was no condition that would unacceptably limit understanding (such as language), verbal communication, or the ability to provide consent.

Data Collection

The subjects were recruited from the lists of patients seen in consultation, hospitalized and referred by the case management nurse, after identification by main diagnosis, according to the 9th International Classification of Diseases (ICD-9). Children with LT-CCCs were identified according to the criteria proposed by Feudtner, Christakis, and Connell (2000), who classified nine organ system–based CCC types: cardiovascular, congenital/genetic, gastrointestinal, hematologic/immunologic, malignant, metabolic, neuromuscular, renal, and respiratory.

The presence of criteria for palliative care was then verified by consulting the patient's clinical records, taking into account the four categories of the ACT estimation method (EAPC Taskforce for Palliative Care in Children, 2007) and the estimated level of care required, according to the degree of specialization required by personnel in this area. In this respect, the first, basic level is termed the palliative approach; the second is that of intermediate attention, in which care duties are shared; the third level, in which specialized care must be provided, is defined according to the clinical diagnosis of the disease and its duration. The main outcome variable was healthcare utilization in the previous 12 months. Other data recorded included medical support devices needed at home and socioeconomic variables such as social status, educational background, age, gender, and distance from the patient's home to healthcare facilities.

Social status was measured by neo-Weberian indicators of occupational social class (CSO-SEE12; Domingo-Salvany et al., 2013). This instrument is composed of seven categories, which for the purposes of our study were combined into four (following the authors' recommendations), and it is the validated method available in Spain for stratifying social class (Domingo-Salvany et al., 2013). It has the limitation that nonworking people cannot be classified, but it has been suggested to overcome this issue with the addition of educational level (Domingo-Salvany et al., 2013).

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After identifying the study sample, these patients' utilization of health services was analyzed by reference to their clinical records, and self-administered questionnaires were delivered to the parents to obtain sociodemographic and socioeconomic data, provide information about the study, and request signed informed consent.

Ethical Considerations

The study was approved by the Granada Ethics & Research Committee (Report No. 0655-N-16). All participants were asked for their consent to be part of the study, and at all times the Helsinki principles and the standards of good practice were complied with.

Data Analysis

According to hospital records, an average of 10,286 patients are treated each year in the pediatric medical and surgical services. Assuming a prevalence of 10% (estimated from a previous pilot study carried out in the same hospital), an alpha value of 0.05, and a precision of 5%, we calculated that a sample group of 137 cases would need to be analyzed to evaluate the number of children and adolescents in our area in need of complex chronic care.

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Descriptive statistics were obtained to identify the characteristics of the sample and the use made of health resources. Differences in terms of sociodemographic characteristics were examined using bivariate analysis based on Student's t test, the Mann-Whitney U test, the Wilcoxon test, or the chi-square test, depending on the normality of the distributions and the nature of the variables compared. One-way analyses of variance were carried out to evaluate frequentation of health services by educational and occupational status, separately for fathers and mothers, and by clinical palliative groups. Analyses were carried out separately for fathers and mothers, with Scheffe, Bonferroni, and Games-Howell post-hoc comparisons, and post-hoc power analyses. Previously, Levene's test to evaluate equality of variances was carried out. Spearman correlations were calculated to determine relationships between the use of different health services.

Finally, multivariate linear regression models were constructed to identify parameters associated with the use of these health services (dependent variable), taking into account sociodemographic factors and disease characteristics as independent variables. Analyses were performed with SPSS version 24 (IBM Corp., Armonk, NY, U.S.A.) and GPower 3.1.

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Results

The sample population of 265 children ranged in age from 0.2 months to 17.3 years, with an average of 7.3 years (*SD* 4.63); 43.4% were female, 56.6% were male, and 89.4% were of Spanish nationality. The average duration of the disease was 63.26 months (*SD* 54.09). Figure S1 is a flow chart for recruitment of patients to this study.

The parents presented with the following sociodemographic characteristics: the fathers' average age was 41.48 years (SD 7.87); 40.3% had attained only a primary school level of education; and 36.1% were in an unskilled occupation. Among the mothers, the average age was 38.57 years (*SD* 7.37). The distribution of educational background was similar, except that 29.7% of mothers had attained a university level of education vs. 22.1% of the fathers; 59.7% of the mothers were unemployed.

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A significant proportion of the children (62.1%) experienced a dispersion of health services, being treated at several centers simultaneously, usually because the hospital has several disconnected buildings. Moreover, 20.8% of the children were referred from other provinces over 100 km from the hospital. Table 1 details the characteristics of the study population.

Characteristics of the Sample

Table 1 AQ19

	Male (*n* = 265)	**Female (*n* = 265)**	***p***
e, mean years (*SD*)[a]	7.39 (4.41)	7.18 (4.91)	.714
Duration of the disease, mean months (*SD*)[a]	59.13 (51.52)	68.65 (57.06)	.156
Parents' age, mean years (*SD*)[a]	44.37 (6.81)	41.52 (6.16)	<.001
Educational qualifications, *n* (%)[b]			
None	13 (4.9)	11 (4.20)	<.001
Primary	104 (40.03)	88(33.50)	
Secondary	28 (10.6)	26 (9.8)	
University	57 (22.10)	78 (29.70)	
Occupation, *n* (%)[b]			
Unemployed or retired	49 (19.20)	157 (59.70)	<.001
Managerial	36 (14.10)	37 (14.10)	
Supervisory, intermediate level	78 (30.60)	37 (14.10)	
Unskilled	92 (36.10)	32 (12.20)	

[a] Student's *t* test.

[b] Chi-square test.

The children in the sample were treated mainly for neurological diseases (35.8%), congenital diseases (23.9%), and oncological diseases (18.9%). According to the classification of palliative diseases, 35.8% of the children were classified as Group 4 (an irreversible but not progressive disease situation, producing complex health needs; this situation is provoked by some neurological diseases or polymorphic syndromes), while 30.2% of the children were classified as Group 2 (suffering a disease that requires prolonged treatment to improve and maintain the quality of life). Group 1 (life-threatening conditions for which curative treatment may be feasible but can fail, where access to palliative care services may be necessary alongside attempts at curative treatment if treatment fails) accounted for 24.9% of children, and Group 3 (progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years) accounted for 9.1%. The outpatient consultations most commonly attended were those of the neurology (32.7%), digestive (17.4%), oncology (16.2%), and rehabilitation areas (9.4%); 75.1% of the children were receiving intermediate or advanced palliative care. Those in ACT-3 presented with the greatest need for advanced palliative care, while those in ACT-2 were the main recipients of basic palliative care (chi-square = 28.28; $p < .0001$).

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Most of the children made chronic use of some form of health technology at home, with the most significant forms being home oxygen therapy (15.5%), percutaneous gastrostomy (13.6%), enteral nutrition (11%), bladder catheter (4.1%), tracheostomy (3.4%), and mechanical ventilation (2.7%).

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In 2015, the children with palliative criteria were treated in the emergency room up to 25 times, requiring up to 74 one-day hospital admissions, 22 hospitalizations (of which 12 were urgent), and 91 visits to specialists through outpatient consultations, producing up to 139 total contacts with the health system.

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There were differences in the use of health resources according to the father's educational background, but they were not statistically significant. However, the educational level of the mothers was associated with significant differences in healthcare utilization (Table S1); thus, the children of mothers who had attended high school or university made greater use of day hospital facilities (mean difference 7.15, p = .011), outpatient consultation (mean difference 13.77; p = .019), and total health care (mean difference 28.44; $p = .01$).

A positive association was observed between level of care and the utilization of health services. Thus, children classified as needing advanced care were more likely to make use of these services, in any of the forms considered, than those receiving intermediate or basic levels of care ($p < .0001$; Table S2).

By groups, a similar pattern was observed. The children classified as Group 1 made significantly greater use of the day hospital and of scheduled hospitalization and had a greater total number of contacts with the health system. On the other hand, those in Group 3 were more likely to require emergency services attention and urgent hospital admission (see Table S2).

The children who had been diagnosed more recently (<45 months) generally made greater use of health resources in terms of day hospital visits ($n = 13.11$, *SD* = 20.63 vs. *n* = 1.94, *SD* = 5.49 among those with a longer history of the disease); scheduled hospitalizations (*n* = 3.85, *SD* = 5.19 vs. *n* = 0.98, *SD* = 1.6); consultations (*n* = 28.32, *SD* = 15.87 vs. *n* = 18.66, *SD* = 10.26), total health contacts (*n* = 50.91, *SD* = 34.37 vs. *n* = 25.74, *SD* = 14.62; $p < .0001$); and urgent hospitalizations ($p < .019$), except in visits to the A&E department.

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Age-adjusted analysis did not reveal any change in the relationship between time elapsed since diagnosis and health services utilization ($p < .0001$). There was a positive correlation between emergency room visits and urgent hospitalizations ($r = .51$, $p < .0001$), and between day hospital admissions and scheduled hospitalizations ($r = .50$; $p < .0001$).

The multivariate linear regression model, constructed to observe factors associated with total contacts with the health system, showed that children with advanced care needs, with a shorter history of disease since diagnosis, who were classed as palliative care Group 1 (e.g., those with advanced oncological diseases with poor prognosis, or with severe heart disease), and whose mothers were older or had a higher level of education had greater contact with the health system. This model presented a high level of predictive capacity ($r^2 = 78.0\%$, $p < .0001$), and it fulfilled all the regression assumptions (Durbin-Watson 2.06, variance inflation factor under 1.30, and homoscedasticity of residuals; Table 2).

Table 2 Healthcare Utilization and Clinical and Socioeconomic Factors

	B	**β**	***p***	**95% confidence interval**	
				Lower bound	**Upper bound**
Mother's age	0.40	0.36	.002	0.15	0.66
Palliative group	−4.07	−0.26	<.001	−6.08	−2.07
Healthcare level	13.92	0.71	<.001	10.81	17.03
Months since diagnosis	−0.11	−0.20	<.001	−0.162	−0.05
Mother's education	2.26	0.19	.019	0.37	4.14

[a] Note

Dependent variable: total healthcare utilization. Multivariate linear regression.

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Discussion

Our study aim was to determine the use of health services for children with severe chronic diseases, seeking to identify patterns of use according to sociodemographic and clinical conditions that could benefit from nursing case management services. Overall, the results obtained reveal important differences in health services utilization.

The sociodemographic profile of our sample did not differ significantly from that of the general population in Spain, according to Eurostat (European Union, 2018). There is a well-established association between socioeconomic status (SES) and health, but less is known about how SES influences the use of health resources, with particular regard to the SES of parents of children with CCCs.

Our analysis shows that the children of parents with higher education levels tend to make greater use of health service resources. This might be due to these parents having greater access to information, and hence to health resources. Such an association, in terms of obtaining support and assistance, has been reported previously (Carnevale, Alexander, Davis, Rennick, & Troini, 2006), but no more recent data in the pediatric population have been found. Furthermore, these parents may also enjoy greater flexibility in the workplace.

Similar results were obtained by the KIDSCREEN 19 project, implemented in 13 European countries, according to which intensity of health services utilization was positively associated with health status and sociodemographic characteristics (Berra et al., 2009). Results of another study, focused on the demand for hospitalization by patients with chronic conditions, carried out in five European countries, showed that the demand variables found were the patient's level of income and educational background (Thygesen et al., 2015). Furthermore, studies have shown that children with chronic diseases who live in more precarious socioeconomic environments have a lower quality of life than those from more favourable ones (Didsbury et al., 2016). These children also XXXXXXXXXX in aspects such as access to health attention, health service preferences, and participation in decision-making (Bona & Wolfe, 2017).

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A large proportion of the mothers in our sample were unemployed, despite having higher education levels. Children with chronic conditions impose greater financial burdens (Medway et al., 2015; Zan & Scharff, 2015), which greatly heightens the probability of employment difficulties (Montes & Halterman, 2011), and this situation usually impacts more severely on the mother than on the father (Hope, Pearce, Whitehead, & Law, 2017).

Interventions to reduce burdens on the family and hospital resources include improving the coordination of care, improving the transition to home care, including the patient in a comprehensive care program, and teaching parents how to manage their child's health (Cohen, Jovcevska, Kuo, & Mahant, 2011; Khandelwal, Benkeser, Coe, & Curtis, 2016). These interventions are at the core of many advanced nursing services. Thus, advanced practice nurses and nurse case managers can help families to proactively identify health changes and to manage and monitor the child's progress (Cady, Kelly, Finkelstein, Looman, & Garwick, 2014).

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In view of the high demand for care and the significant consumption of health resources by the patients in our sample, care coordination needs serious improvement, and services should be created to provide comprehensive care for this population, including transitional care, designed not only for patients with short life expectancy, but also for those who survive with severe chronic diseases, and who are predisposed to major utilization of healthcare resources (Smith et al., 2015).

Finally, we believe that it is necessary to consider the variable “time elapsed since diagnosis” as a relevant factor in the use of health service resources. In this respect, we observed that the children who had been diagnosed more recently (<45 months) generally made greater use of health resources, except for visits to the A&E department. A possible explanation for this is that when the diagnosis is recent, the parents are less well informed about management of the symptoms presented, and therefore a greater number of diagnostic tests are performed.

Limitations

In our study, no evaluation was made of the suitability of the care provided. This question should be addressed in future research, together with other methodological approaches. For example, health service users and providers might consider the hospital to be the most appropriate environment for care, due to the severity of the disease or the complexity of the patient's needs, even if many months of hospital care are needed (Berry et al., 2011).

We analyzed health resources with respect to a study period of 1 year; in subsequent analysis, a longer period might usefully be considered to help contextualize the findings. Finally, this study is based on retrospective data, recorded in the hospital database and in the patients’ clinical records; however, it does not take into account the consumption of other resources (e.g., those provided by private healthcare services) or of outpatient or community care.

Despite these limitations, to our knowledge, this is the first study to provide information on the use of health resources for children in need of advanced care due to the presence of complex chronicity and socioeconomic determinants.

Conclusions

Children with complex chronic life-threatening diseases make considerable and wide-ranging use of health resources, and some socioeconomic factors are associated with this pattern of use. These diseases pose a major challenge both to the patient's family and to healthcare providers, across international healthcare systems. Policymakers should design and provide comprehensive and coordinated systems of care for this population.

Future research in this field should seek to improve methods to identify case-finding children with complex chronicity with reliable and valid methods, to monitor their use of health services, and to assess whether current care systems are meeting patients' needs, taking into account the inequalities arising from socioeconomic circumstances, adopting measures to address these factors, and seeking the active participation of parents and children in this field. Finally, shared decision making and acceptability of alternatives for care should be investigated, taking into account social disparities.

Clinical Resources

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- Canadian Association of Paediatric Health Centres. Guideline for the management of medically complex children and youth through the continuum of care. https://bit.ly/2V02OyG
- European Association of Palliative Care. https://www.eapcnet.eu/
- Straus, E., & Baird, J. Clinical practice guideline for support of families of children with chronic conditions. Journal of Pediatric Nursing, 43, 146. https://www.pediatricnursing.org/article/S0882-5963(18)30430-5/fulltext

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Supplementary Material

Figure S1. Recruitment of patients. Table S1. Health Care Utilisation and Sociodemographic Characteristics

Table S2. Health Care Utilisation by Palliative Care Group and by Health Care Needs Group

References

Alcalá, C., José, F., García Fernández de Villalta, M., Escosa García, L., Rodríguez Alonso, A., Velasco, A., & Adolfo, L. (2018). Unidad de niños con patología crónica compleja. Un modelo necesario en nuestros hospitales. Anales AQ30 de Pediatría, 88(1), 12–18. https://doi.org/10.1016/j.anpedi.2017.04.002

American Academy of Pediatrics. (2013). Pediatric palliative care and hospice care commitments, guidelines, and recommendations. Pediatrics, 132 (5). Retrieved from http://pediatrics.aappublications.org/content/132/5/966?trendmd-shared=0&utm_source=TrendMD&utm_medium=TrendMD&utm_campaign=Pediatri
AQ31

Ananth, P., Melvin, P., Feudtner, C., Wolfe, J., & Berry, J. G. (2015). Hospital use in the last year of life for children with life-threatening complex chronic conditions. Pediatrics, 136(5), 938–946. https://doi.org/10.1542/peds.2015-0260 AQ32

Andersen, R. M. (1995). Revisiting the behavioral model and access to medical care: Does it matter? Journal of Health and Social Behavior, 36(1), 1–10. AQ33 https://doi.org/10.2307/2137284

Berra, S., Tebé, C., Erhart, M., Ravens-Sieberer, U., Auquier, P., Detmar, S., … European KIDSCREEN group. (2009). Correlates of use of health care services by children and adolescents from 11 European countries. Medical Care, 47(2), 161–167. https://doi.org/10.1097/mlr.0b013e3181844e09

Berry, J. G., Hall, D. E., Kuo, D. Z., Cohen, E., Agrawal, R., Feudtner, C., … Neff, J. (2011). Hospital utilization and characteristics of patients experiencing recurrent readmissions within children's hospitals. Journal of the American Medical Association, 305(7), 682–690. https://doi.org/10.1001/jama.2011.122

Bona, K., & Wolfe, J. (2017). Disparities in pediatric palliative care: An opportunity to strive for equity. Pediatrics, 140(4), e20171662. https://doi.org/10.1542/peds.2017-1662

Cady, R. G., Kelly, A. M., Finkelstein, S. M., Looman, W. S., & Garwick, A. W. (2014). Attributes of advanced practice registered nurse care coordination for children with medical complexity. Journal of Pediatric Health Care, 28(4), 305–312. https://doi.org/10.1016/j.pedhc.2013.06.005

Carnevale, F. A., Alexander, E., Davis, M., Rennick, J., & Troini, R. (2006). Daily living with distress and enrichment: The moral experience of families with ventilator-assisted children at home. Pediatrics, 117(1), e48–e60. https://doi.org/10.1542/peds.2005-0789

Cohen, E., Jovcevska, V., Kuo, D. Z., & Mahant, S. (2011). Hospital-based comprehensive care programs for children with special health care needs: A systematic review. Archives of Pediatrics & Adolescent Medicine, 165(6), 554–561. https://doi.org/10.1001/archpediatrics.2011.74

Cohen, E., Kuo, D. Z., Agrawal, R., Berry, J. G., Bhagat, S. K. M., Simon, T. D., & Srivastava, R. (2011). Children with medical complexity: An emerging population for clinical and research initiatives. Pediatrics, 127(3), 529–538. https://doi.org/10.1542/peds.2010-0910

Didsbury, M. S., Kim, S., Medway, M. M., Tong, A., McTaggart, S. J., Walker, A. M., … Wong, G. (2016). Socio-economic status and quality of life in children with chronic disease: A systematic review. Journal of Paediatrics and Child Health, 52(12), 1062–1069. https://doi.org/10.1111/jpc.13407

Domingo-Salvany, A., Bacigalupe, A., Carrasco, J. M., Espelt, A., Ferrando, J., & Borrell, C. (2013). Proposals for social class classification based on the Spanish National Classification of Occupations 2011 using neo-Weberian and neo-Marxist approaches. Gaceta Sanitaria, 27(3), 263–272.

EAPC Taskforce for Palliative Care in Children. (2007). IMPaCCT: Standards for paediatric palliative care in Europe. European Journal of Palliative Care, 14(3), 109–114.

EAPC Taskforce for Palliative Care in Children. (2009). Palliative care for infants, children and young people: The facts. Fondazione Maruzza Lefebvre D'Ovidio Onlus. Retrieved from http://www.eapcnet.eu/LinkClick.aspx?fileticket=DeiV2yhtOZA%3D

European Union. (2018). Education and training statistics. Retrieved from http://ec.europa.eu/eurostat/web/education-and-training

Feudtner, C., Christakis, D. A., & Connell, F. A. (2000). Pediatric deaths attributable to complex chronic conditions: A population-based study of Washington State, 1980–1997. Pediatrics, 106(1 Pt 2), 205–209.

Feudtner, C., Kang, T. I., Hexem, K. R., Friedrichsdorf, S. J., Osenga, K., Siden, H., … Wolfe, J. (2011). Pediatric palliative care patients: A prospective multicenter cohort study. Pediatrics, 127(6), 1094–1101. https://doi.org/10.1542/peds.2010-3225

Groh, G., Feddersen, B., Führer, M., & Borasio, G. D. (2014). Specialized home palliative care for adults and children: Differences and similarities. Journal of Palliative Medicine, 17(7), 803–810. https://doi.org/10.1089/jpm.2013.0581

Hope, S., Pearce, A., Whitehead, M., & Law, C. (2017). Effects of child long-term illness on maternal employment: Longitudinal findings from the UK Millennium Cohort Study. European Journal of Public Health, 27(1), 48–52. https://doi.org/10.1093/eurpub/ckw132

Hudon, C., Chouinard, M.-C., Lambert, M., Diadiou, F., Bouliane, D., & Beaudin, J. (2017). Key factors of case management interventions for frequent users of healthcare services: A thematic analysis review. BMJ Open, 7(10), e017762. https://doi.org/10.1136/bmjopen-2017-017762

Institute of Medicine. (2011). The future of nursing: Leading change, advancing health. Washington, DC: National Academies Press.
AQ34 https://doi.org/10.17226/12956

Johnston, E. E., Alvarez, E., Saynina, O., Sanders, L., Bhatia, S., & Chamberlain, L. J. (2017). Disparities in the intensity of end-of-life care for children with cancer. Pediatrics, 140(4). https://doi.org/10.1542/peds.2017-0671

Kaye, E. C., Rubenstein, J., Levine, D., Baker, J. N., Dabbs, D., & Friebert, S. E. (2015). Pediatric palliative care in the community. CA: A Cancer Journal for Clinicians, 65(4), 316–333. https://doi.org/10.3322/caac.21280

Khandelwal, N., Benkeser, D. C., Coe, N. B., & Curtis, J. R. (2016). Potential influence of advance care planning and palliative care consultation on ICU costs for patients with chronic and serious illness. Critical Care Medicine, 44(8), 1474–1481. https://doi.org/10.1097/CCM.0000000000001675

Looman, W. S., Presler, E., Erickson, M. M., Garwick, A. E., Cady, R. G., Kelly, A. M., & Finkelstein, S. M. (2013). Care coordination for children with complex special health care needs: The value of the advanced practice nurse's enhanced scope of knowledge and practice. Journal of Pediatric Health Care, 27(4), 293–303. https://doi.org/10.1016/j.pedhc.2012.03.002

Medway, M., Tong, A., Craig, J. C., Kim, S., Mackie, F., McTaggart, S., … Wong, G. (2015). Parental perspectives on the financial impact of caring for a child with CKD. American Journal of Kidney Diseases, 65(3), 384–393. https://doi.org/10.1053/j.ajkd.2014.07.019

Montes, G., & Halterman, J. S. (2011). The impact of child care problems on employment: Findings from a national survey of US parents. Academic Pediatrics, 11(1), 80–87. https://doi.org/10.1016/j.acap.2010.11.005

Nageswaran, S., Silver, E. J., & Stein, R. E. K. (2008). Association of functional limitation with health care needs and experiences of children with special health care needs. Pediatrics, 121(5), 994–1001. https://doi.org/10.1542/peds.2007-1795

National Association of Pediatric Nurse Practitioners. (2009). NAPNAP position statement on reimbursement for nurse practitioner services. Journal of Pediatric Health Care, 23(6), A13–A14. https://doi.org/10.1016/j.pedhc.2009.06.013

Observatorio de la Infancia en Andalucía. (2016). Datos de población municipal 2015: Granada. Junta de Andalucía. Consejería de Igualdad y Políticas Sociales. Escuela Andaluza de Salud Pública. Retrieved from http://www.observatoriodelainfancia.es/oia/esp/documentos_ficha.aspx?id=4890 AQ35

Ogelby, M., & Goldstein, R. D. (2014). Interdisciplinary care: Using your team. Pediatric Clinics of North America, 61(4), 823–834. https://doi.org/10.1016/j.pcl.2014.04.009

Salisbury, C. (2012). Multimorbidity: Redesigning health care for people who AQ36 use it. Lancet, 380(9836), 7–9.

Smith, A. G., Andrews, S., Bratton, S. L., Sheetz, J., Feudtner, C., Zhong, W., & Maloney, C. G. (2015). Pediatric palliative care and inpatient hospital costs: A longitudinal cohort study. Pediatrics, 135(4), 694–700. https://doi.org/10.1542/peds.2014-3161

Steele, R., Siden, H., Cadell, S., Davies, B., Andrews, G., Feichtinger, L., & Singh, M. (2014). Charting the territory: Symptoms and functional assessment in children with progressive, non-curable conditions. Archives of Disease in Childhood, 99(8), 754–762. https://doi.org/10.1136/archdischild-2013-305246

AQ37

Thygesen, L. C., Christiansen, T., García-Armesto, S., Angulo-Pueyo, S., Martínez-Lizaga, L., & Bernal-Delgado, E. (2015). Potentially avoidable hospitalizations in five European countries in 2009 and time trends from 2002 to 2009 based on administrative data. European Journal of Public Health, 25(Suppl. 1), 35–43.

Walter, J. K., DeCamp, L. R., Warrier, K. S., Murphy, T. P., & Keefer, P. M. (2013). Care of the complex chronically ill child by generalist pediatricians: Lessons learned from pediatric palliative care. Hospital Pediatrics, 3(2), 129–138.

Zan, H., & Scharff, R. L. (2015). The heterogeneity in financial and time burden of caregiving to children with chronic conditions. Maternal and Child Health Journal, 19(3), 615–625. https://doi.org/10.1007/s10995-014-1547-3