

Children with medical complexity: the change in the pediatric epidemiology

Rino Agostiniani^{1,2}, Laura Nanni², Tommaso Langiano¹

¹Meyer Children's Hospital, Florence, Italy

²Pediatric Department, San Jacopo Hospital, Pistoia, Italy

Proceedings

Proceedings of the 10th International Workshop on Neonatology · Cagliari (Italy) · October 22nd-25th, 2014

The last ten years, the next ten years in Neonatology

Guest Editors: Vassilios Fanos, Michele Mussap, Gavino Faa, Apostolos Papageorgiou

Abstract

In the last years, epidemiological landscape of pediatric illness is changed; we are facing a progressive raising of the number of children affected by chronic illness (children with special health care needs [CSHCN]), mainly due to the amelioration in surviving and in care. These patients have become the majority of the inpatients in some specialist hospitals, like the Meyer Children's Hospital (Florence, Italy), in 2012.

One important group of CSHCN is represented by the children who are most medically fragile and have the most intensive health care needs (children with medical complexity [CMC]). In these patients, the complexity of the pathological framework frequently results in a plenty of visits and tests, with high risk of redundant and expensive cares.

They also need outside support networks such as advocacy and accommodations at school, at home, in social life.

The CMC needs specific skill and new strategies that could involve pediatricians in hospital as in home care.

The professional competencies are ready but a clear and shared strategy is lacking.

Keywords

Children, medical complexity, home care, pediatric network, chronic illness, expensive care.

Corresponding author

Rino Agostiniani, Meyer Children's Hospital, Florence, Italy, and Pediatric Department, San Jacopo Hospital, Pistoia, Italy; email: rinoagostiniani@alice.it.

How to cite

Agostiniani R, Nanni L, Langiano T. Children with medical complexity: the change in the pediatric epidemiology. *J Pediatr Neonat Individual Med.* 2014;3(2):e030230. doi: 10.7363/030230.

Introduction

In the web site of NACHRI (National Association of Children's Hospital and Related Institution) is told the story of R., a ten-year-old girl born with a rare, progressive disease called CLOVE Syndrome. Since she was 3 months old, she undergone 16 major surgeries and more than 40 MRIs to treat the overgrowth of benign lesions caused by the disease. She saw 14 different types of specialists; they were in addition to her primary pediatrician, her pharmacists, and her physical and occupational therapists. For her care, she and her family are a frequent traveler [1]. R. is the testimonial of NACHRI awareness campaign aimed to improve care of children with medical complexity. That is due to the epidemiological relevance of problem and to the need to radically improve care organization for these kind of patients. Indeed, children with special health care needs (CSHCN) – defined as children who have (or are at risk of) a chronic physical, developmental, behavioral, or emotional condition and require health care and related services of a type or amount beyond that generally required by children – constitute 18% of US children [2]. One important group of CSHCN is represented by the children who are most medically fragile and have the most intensive health care needs, e.g. children who have a congenital or acquired multisystem disease, a severe neurologic condition with marked functional impairment, or patients with cancer/cancer survivors with ongoing disability in multiple areas [2]. These children are defined “children with medical complexity” (CMC). CMC are a growing population. In USA approximately 3 million of the nation's 76 million children have medical complexity, and CMC are increasing at a rate of about 5% annually, outpacing the growth rate of children as a whole [1]. The number of these children is growing due to the improved care and

to the higher survival rates. This epidemiological situation is a challenge for pediatricians: CMC need non-stop care and a multiple specialistic approach; they also need outside support networks such as advocacy and accommodations at school, at home, in social life. Basically, CMC need a system that enables long-term continuity of care within the same network, making it possible for children and their families to sustain a relationship with their care providers to coordinate care needs over years or even decades. The epidemiology of childhood is changed: the incidence of serious acute illness in children has fallen while the prevalence of chronic disease has risen. These trends have resulted in a growing concentration of serious childhood morbidity and mortality into chronic disorders [3]. However, the current organization of pediatric care is focused on acute illness, so each therapeutic or diagnostic event (as outpatient or inpatient) is not related to the framework of the medical complexity. The lack of coordination could rise the risk of unnecessary repetition of tests and frequent or prolonged hospitalizations, which can lead to a higher utilization of health resource [4].

Although there is not yet a standard definition of medical complexity, four cardinal domains characterize these patients [5]:

1. CMC have 1 or more chronic clinical condition(s) (diagnosed or unknown), that are severe and/or associated with medical fragility (e.g., high morbidity and mortality rates);
2. CMC are characterized by substantial family-identified health care service needs (e.g., medical care, specialized therapy, and educational needs), that have a significant impact on the family unit;
3. for CMC, the functional limitations are usually severe and may require assistance from technology (e.g., a tracheostomy tube, feeding tube, or a wheelchair).
4. CMC typically have high utilization of health resources (e.g., frequent or prolonged hospitalization, multiple surgeries). The intensity of health care is substantial when compared with other populations of CSHCN.

The project of NACHRI for CMC is grounded on three principal points:

1. create a national database to measure the care and costs of CMC and to share information. The health care system will benefit from a unique source of information (a regional-level database on this relatively small subset of patients is insufficient to drive meaningful

evidence-based results), that can helping care providers to continuously monitor and improve quality of care, to advance best practices and to set national standards for the care of these children;

2. create regional network to share with health provider clinical data about patient's care;
3. create home care services to mitigate the severity of the child's chronic health conditions and to effectively meet the needs of the child and family in a timely manner and to maximize the child's functional abilities and minimize avoidable hospitalizations as well as other ineffective and/or unnecessary use of health resources.

Italian data

Some tools for estimate the epidemiology of CMC, like Clinical Risk Groups (CRGs) are commonly used in USA, but are not available in Italy. We can use SDO (*scheda di dimissione ospedaliera*: hospitalization discharge chart) and discriminate between acute and chronic illness by the use of CCI (chronic condition indicator) developed by AHRQ (Agency for Healthcare Research and Quality). The chronic illness is defined as a disease that persists for at least 12 months.

In **Tab. 1**, you can find the trend in the number of hospital discharges related to chronic disease between 2010 and 2012 at Meyer Children's Hospital. In the last three years, the annual amount of admissions was the same, but the number of inpatient for chronic disease has grown by 4.4% and they spent more time than previously at the hospital (7.8%). The number of days of hospitalization for chronic illness was 49.9% of the whole in 2010 vs. 54.3% in 2012, so that the care for inpatient for chronic disease overcame the care for acute illness. The same trend was found for the

outpatients (64%) affected by chronic disease and for the patients coming from other regions (34% of inpatient for chronic disease).

Tab. 2 explains the diagnostic subgroups for chronic illness at Meyer Children's Hospital in 2012: the inborn malformations are the first one for frequency (35%).

Overall, the admission for chronic disease at Italian children's hospitals was 20% of total admissions in 2010 and was 22% of total days spent in hospital (data from National Healthcare department [6]).

Tab. 3 explains the diagnostic subgroups for pediatric chronic illness in all Italian hospitals in 2010: the respiratory diseases are the first one for frequency.

Although the data are referred to different years, this difference between Meyer Children's Hospital and Italian hospitals can be explained by a real difference in casistic between Meyer and other hospitals.

Conclusion

The epidemiology of childhood is changing: the hospital admission of children affected by chronic diseases are more frequent and more relevant than those of children with acute diseases. Particularly CMC are growing in number and needs.

Therefore, adequate and specific skills are necessary for facing chronic disease and for CMC.

The clinical complexity of this kind of patients needs a multilevel approach to the diagnosis, to the clinical stabilization, to the establishment of care program and to the implementation of home care.

The common level of the therapy is particularly correlated to the specific age of patients, so that the key role should belong to a regional pediatric network, involving children's hospitals, pediatric practitioners and home care nurses.

Table 1. Trend of admission and days of hospitalization for chronic and acute disease (Meyer Children's Hospital, 2010-2012).

Meyer Children's Hospital Inpatient	Year 2010	Year 2012	Δ% 2012 vs. 2010
Total discharged	8,811	8,810	-0.0
Chronic cases	4,183	4,367	4.4
Acute cases	4,628	4,443	-4.0
Total hospitalization' days	50,139	49,668	-0.9
Hospitalization's days for chronic cases	25,002	26,948	7.8
Hospitalization's days for acute cases	25,137	22,720	-9.6

Table 2. Distribution of cases and days of hospitalization for diagnostic subgroups (Meyer Children's Hospital, 2012).

Rank	Diagnostic subgroups	Year 2012	%
1	Inborn malformations	1,567	35.8
2	Diseases of nervous system and sense organs	633	14.5
3	Factors influencing health status and use of health services	416	9.5
4	Respiratory diseases	375	8.6
5	Mental disorders	314	7.2
6	Endocrine, metabolic and nutritional disease and disorders of immune system	239	5.5
7	Cancer	184	4.2
8	Diseases of the blood and hematopoietic system	184	4.2
9	Cardiovascular diseases	142	3.3
10	Gastrointestinal diseases	122	2.8
11	Musculoskeletal diseases	90	2.1
12	Genitourinary diseases	85	1.9
13	Others	16	0.4

Table 3. Distribution of pediatric chronic cases for diagnostic subgroups in Italian hospitals (year 2010) [6].

Rank	Diseases	%
1	Respiratory diseases	28.1
2	Inborn malformations	21.2
3	Diseases of nervous system and sense organs	14.1
4	Mental disorders	7.9
5	Factors influencing health status and use of health services	5.4
6	Gastrointestinal diseases	5.2
7	Cancer	3.8
8	Cardiovascular diseases	3.4
9	Diseases of the blood and hematopoietic system	3.4
10	Musculoskeletal diseases	3.1
11	Others	4.4

As recently stated by Palfrey, “the big issue is not whether pediatricians have the motivation. Nor is the question whether educational tools are available to boost community health and advocacy know-how. The big issue is whether the pediatric field has a strategy to integrate our child health activities into the changing health care system” [7].

Declaration of interest

The Author declares that there is no conflict of interest.

References

1. <https://www.childrenshospitals.net/Am/Template.cfm?Section=Home&id=1690>, last access: July 2014.
2. McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck PW, Perrin JM, Shonkoff JP, Strickland B. A new definition of children with special health care needs. *Pediatrics*. 1998;102(1 pt 1):137-40.
3. Wise PH. The future pediatrician: the challenge of chronic illness. *J Pediatr*. 2007;151(5 Suppl):S6-10.
4. Srivastava R, Stone BL, Murphy NA. Hospitalist care of the medically complex child. *Pediatr Clin North Am*. 2005;52(4):1165-87.
5. Cohen E, Kuo DZ, Agrawal R, Berry JG, Bhagat SKM, Simon TD, Srivastava R. Children With Medical Complexity: An Emerging Population for Clinical and Research Initiatives. *Pediatrics*. 2011;127:529-38.
6. http://www.salute.gov.it/portale/documentazione/p6_2_2_1.jsp?lingua=italiano&id=1690, last access: July 2014.
7. Palfrey JS. Transforming child health care. *Pediatrics*. 2013; 132(6):1123-4.