



## EDITORIAL

### Mortality of patients with chronic disease: an increasing problem ☆,☆☆



### Mortalidade de pacientes com doenças crônicas: um problema crescente

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Most recent health reports by the World Health Organization indicate that childhood mortality rates worldwide have been reducing in the last decades. This fact is caused especially by the decrease in mortality related to some acute diseases as respiratory infections, diarrhea, and prematurity.<sup>1</sup> Conversely, the percentage of child deaths related to chronic disease is stable or even increasing. Several studies have shown that, in some countries, child deaths related to chronic conditions is close to 50%.<sup>2,3</sup>

The growing number of pediatric patients with chronic conditions not only entails an increase in mortality, but also a higher consumption of health resources in certain hospitalization areas, such as in pediatric intensive care units (PICUs). The study published by O'Brien et al. indi-

cates that 46% of patients admitted to PICUs present at least one chronic health problem, and these patients have higher mortality rates and longer hospitalization times.<sup>4</sup> In our experience among patients requiring long term admissions in PICUs, 81.9% of them have different chronic conditions.<sup>5</sup>

The study published in this issue by Ramos et al. is the first to be carried out in the Latin American region analyzing mortality among adolescent and young adults with chronic diseases.<sup>6</sup>

Despite the limitations of that study, such as its retrospective and unicentric design, it had a long observation time and included a large cohort of patients. However, from the socioeconomic standpoint, Latin America is a very heterogeneous region and important differences exist between the different national health systems in the continent. Further multicentric international studies are required to characterize mortality among young patients with chronic diseases. Nonetheless, the retrospective design and the long time observation period have permitted to describe how mortality has decreased in a very specific group of patients, such as in those with human immunodeficiency virus (HIV).<sup>6</sup>

The authors have compared two different groups of patients: young adolescents (those aged between 10 and 14

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years) and late adolescents/young adults (those between 15 and 20 years old). As expected, older patients had a longer follow-up time and higher number of previous admissions. Other differences between those groups of patients were more remarkable, such as a lesser use of palliative care and greater use of renal replacement therapies, vasoactive drugs, and blood product transfusions in the young adolescent group. Despite the fact that the authors indicated that the higher use of palliative care in the oldest patients might be related to the high frequency of neoplastic diseases, no differences in the rate of neoplastic diseases were observed between the groups.<sup>6</sup>

The development of pediatric palliative care programs has proved to decrease incidence and length of hospital admissions, and thus medical assistance costs related to chronically ill pediatric patients.<sup>7,8</sup> A recently published study by Connor et al. estimates global and country specific palliative care needs.<sup>9</sup> This study established a global rate of pediatric patients needing palliative care on 43 per each 10,000 children between 0 and 19 years old. This same study suggests a rate for Brazil that is far lower, at 27.2 per each 10,000 children a rate, similar to other countries in the region as Argentina (29.1 per each 10,000).

The study by Ramos et al. analyzes specifically those patients in which autopsy information was available, comparing the autopsy results with the diagnoses established in the death certificates.<sup>6</sup> It is noteworthy that 41.3% of postmortem studies showed discordance with the clinical pre-mortem diagnose. However, only a small proportion (5.2%) of these discordances might have affected patient survival. Caution must be taken before generalizing this high rate of disagreement between clinical diagnoses and autopsy results, as autopsy was performed in only 11% of.

The study by Ramos et al. includes only pediatric patients with chronic conditions who deceased at the hospital, but we have to remark that an important proportion of patients with chronic illnesses die at places other than the hospital. Forjaz et al. have studied the places where pediatric chronic patients die in Portugal during a 25 years long period (1987–2011).<sup>3</sup> That study showed that, in Portugal, there is an increasing trend toward pediatric chronic patients deceasing at hospitals. The authors of that study indicated as the main cause of this trend the lack of specific pediatric palliative care programs. Studies performed in other countries show similar results, with a higher proportion of pediatric patients with chronic conditions dying at hospitals compared to those dying at their homes.<sup>10</sup> In this sense, it is important to highlight the study by Håkanson et al., which compared the place of death of pediatric patients with chronic diseases among 11 different countries.<sup>11</sup>

At the hospital level, pediatric patients with chronic pathologies can die in very different hospitalization areas and clinical situations. The work by Ramos et al. specifically describes rate of patients requiring intensive care during their last admission, being this rate high (between 47% and 60%) and higher in the youngest patients group.<sup>6</sup> However, besides the location and support measures during the period prior to death, some very important aspects of the way patients have deceased have not been studied.

Meert et al. have analyzed death causes in PICUs from seven different centers in USA. That study showed that 83% of patients dying after limitation of support and 81% of those

dying after withdrawal of treatment were affected by a chronic illness, while this proportion decreased to 70% and 29% among patients dying after cardiopulmonary resuscitation failure or brain death, respectively.<sup>12</sup>

Other unicentric study carried out in the United States found that 53.3% of children and young adults with chronic conditions deaths took place at PICUs; 27.9% of the patients received intensive care in their last two days of life, but 50% of patients died after withdrawal of vital support measures.<sup>10</sup>

Regarding the causes of chronic disease in the patients studied by Ramos et al. cancer accounted for more than 50% of patients, even though this pathology was the underlying cause of death in only 27% of patients.<sup>6</sup> In turn, it is remarkable the existence of a small percentage (5%) of patients with rheumatological diseases, and that neurological pathologies did not account for an important percentage of patients, as observed by other authors.<sup>6</sup> In the study by DeCoursey et al., 23.7% of patients presented progressive diseases of central nervous system, 16.7% non-progressive encephalopathy, and 11.4% neuromuscular diseases.<sup>10</sup>

Therefore, the study by Ramos et al. highlights the need of addressing the issue of chronic pathology in the pediatric age. Prospective multicenter studies analyzing mortality, causes, and specially the way of dying in acute and chronic pediatric patients are needed to characterize death in the pediatric population. These studies can allow optimizing the attention provided to dying patients, adapting socio-economic and healthcare resources to the specific needs of each region.

As Suttle et al. point out,<sup>13</sup> it is also necessary that physicians in units where pediatric patients die have adequate training and knowledge about current recommendations and policies. Adequate care of these patients must be provided not only from the medical but also from the psychosocial standpoint, both for the patients and their families. Similarly, it is very important for the care providers to have adequate training on ethical and legal issues related to end of life care in pediatric patients.

## Conflicts of interest

The authors declare no conflicts of interest.

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