



## SCIENTIFIC LETTER

## The Paediatric Palliative Care Unit has been transformed into Home Care Unit during the COVID-19 pandemic. Is this transformation for the foreseeable future?

### Transformación de una Unidad de Cuidados Paliativos Pediátricos en Unidad de Atención Domiciliaria a raíz de la pandemia COVID-19. ¿llegó para quedarse?\*



Dear Editor:

In the first wave of the coronavirus disease 2019 (COVID-19) pandemic, the declaration of the state of alert in Spain and the imposition of a lockdown on the population demanded the modification of multiple health care procedures and structures. In our hospital, we came to consider that home care, which was more developed at the time for adult patients,<sup>1,2</sup> could be a useful alternative to face the challenges brought on by the lockdown. This article briefly describes the transformation of a paediatric palliative care unit (PPCU) into a paediatric home health care (PHHC) team and its operation from the start of the confinement (March 16) and May 24 (end of “phase 0” of the “reopening”).

Our hospital has a catchment population of 261 632 inhabitants, 44 345 aged less than 18 years. An interdisciplinary PHHC team was formed, comprised of 2 paediatricians, 1 nurse and 1 clinical psychologist, through the transformation of the PPCU (which only had 1 paediatrician on staff). This team provided home-based care during diagnosis or followup to patients with acute or chronic disease (Table 1) referred from different paediatric speciality clinics (Table 2), in addition to continuing to provide the home-based care that the PPCU had been delivering before the pandemic and supporting other units, such as the human milk bank of Castilla y León. Our hospital already offered home-based and hospital-at-home care through the PPCU, but the adaptation to deliver care in other fields proved essential.

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**Table 1** Clinical conditions or patients that could be managed through paediatric hospital-at-home care. Adapted from Sánchez Etxaniz et al.<sup>1</sup>

- Early discharge with home monitoring of a wide range of patients with acute or chronic disease (multimorbidity, frailty syndrome, followup of oncological, neurologic, cardiovascular, respiratory disease, etc).
- Monitoring and management of patients with respiratory devices at home: oxygen therapy, inhaled or nebulised treatment, invasive or non-invasive mechanical ventilation, with or without a tracheotomy.
- Early discharge of healthy preterm and very-low-birth-weight (1600–2000 g) infants.
- Administration, monitoring and management of home enteral and parenteral nutrition.
- Complex wound care: surgical wounds, ostomy care, pressure ulcers in bedridden patients, burns etc.
- Administration of treatment (chemotherapy, blood products, antibiotherapy) by the enteral or parenteral route (intramuscular, subcutaneous, central or peripheral intravenous access) in patients with acute or chronic disease.
- Monitoring of ostomies (gastrostomy, tracheostomy).
- Collection of blood and microbiological samples.
- Support to mothers that donate human milk to the bank.
- Monitoring of infants at risk of sudden infant death syndrome.
- Palliative care.

In every instance, care delivery included education of caregivers to improve safety and autonomy and emotional support of caregivers.

The PHHC team managed 2 human milk donors and 53 paediatric patients. Of this caseload, 43.6% (24 patients) resided in rural settings. The mean distance between the hospital and the home was 7.2 km (SD, 7.1; range, 0.8–46.1 km). The mean age of the paediatric patients was 7.2 years (SD, 5.2; range, 2 months–20 years), and 50.9% were female.

Of all the paediatric patients 32.1% (17/53) had been patients of the PPCU. Most of them (12/17; 70.6%) received level III care services (hospital-at-home), and were distributed as follows based on the classification of the Association for Children’s Palliative Care: ten patients in group 4, two in group 3, two in group 2 and three in group 1. Another 36 paediatric patients were referred expressly to the PHHC team, including 5 managed by the PPCU (group 2) (Table 2).

**Table 2** Referral source, clinical conditions, medical devices and procedures in paediatric home health care

Referral source (n, %)	Clinical conditions (n, %)	Performed procedures (n, %)	Medical devices (n, %)
Neurology, 19 (34.5%)	<b>ACUTE, 12 (21.8%):</b>	<b>Two or more procedures 28 (50.9%; range, 1-5)</b>	<b>Device, 23 (41.8%)</b>
Endocrinology, 8 (14.5%)	Number of conditions, mean	<b>Blood draw:</b>	<b>2 or more devices, 16 (29.1%)</b>
Gastrointestinal, 7 (12.7%)	1.1 (SD, 0.7)	- Peripheral blood, priority and urgent care, 32 (58.2%)	- Suction aspirator, 12 (21.8%)
Haematology, 6 (10.9%)	Multiple morbidity, 3 (25%)	- Family genetic testing, 2 (3.6%)	- Inhaler, 11 (20%)
Infectious disease, 2 (3.6%)	- Gastrointestinal, 6 (50%)	- From central access line, 6 (10.9%)	- Vital signs monitor, 10 (18.2%)
Neonatology,* 2 (3.6%)	- Haematological, 2 (16.7%)	- Blood tests in human milk donor, 2 (3.6%)	- Gastrostomy, 10 (18.2%)
Pulmonology, 2 (3.6%)	- Allergic, 1 (8.3%)	<b>Nasopharyngeal secretion for SARS-CoV-2 PCR:</b>	- Long-term venous catheter, 10 (18.2%)
Oncology, 2 (3.6%)	- Dermatological, 1 (8.3%)	- Clinical suspicion and before scheduled/oncological admissions 4 (7.3%)	- Oxygen therapy, 8 (14.5%)
Rheumatology, 2 (3.6%)	- Immunological, 1 (8.3%)	- Household members 1 (1.8%)	- Cough assist machine, 6 (10.9%)
Cardiology, 1 (1.8%)	- Neurologic, 1 (8.3%)	<b>Biological sample collection (urine and stool), 2 (3.6%)</b>	- Non-invasive ventilation, 5 (9.1%)
Dermatology, 1 (1.8%)	- Respiratory, 1 (8.3%)	<b>Heparinization of long-term venous catheter (Port-a-Cath® reservoir) 8 (14.5%)</b>	- Home parenteral nutrition, 1 (1.8%).
Metabolic disease, 1 (1.8%)	<b>CHRONIC, 43 (78.2%):</b>	<b>Wound care,** 4 (7.3%)</b>	
Nephrology 1 (1.8%)	Number of conditions, mean	<b>Telephonic support,*** 19 (34.5%)</b>	
Psychiatry, 1 (1.8%)	2.1 (SD, 1.3)	<b>Psychological and spiritual support, 8 (14.5%)</b>	
	Multiple morbidity, 25 (58.1%)	<b>Bereavement services, 2 (3.6%)</b>	
	- Neurologic 21 (48.8%)	<b>Coordination with multidisciplinary team, 21 (38.2%)</b>	
	- Gastrointestinal, 13 (30.2%)	<b>Administration of botulinum toxin under sedation, 1 (1.8%)</b>	
	- Endocrine, 11 (25.6%)	<b>Education and management:</b>	
	- Respiratory, 11 (25.6%)	- Initiation of ketogenic diet, 2 (3.6%)	
	- Oncological, 10 (23.3%)	- Cough assist machine, 4 (7.3%)	
	- Genetic, 5 (11.6%)	- Suction aspirator, 5 (9.1%)	
	- Metabolic, 4 (9.3%)	- Gastrostomy 7 (12.7%)	
	- Cardiological, 3 (7%)	- Home non-invasive ventilation, 3 (5.5%)	
	- Psychiatric, 3 (7%)	- Home enteral nutrition, 7 (12.7%)	
	- Immunological, 3 (7%)	- PCA, 1 (1.8%)	
	- Dermatological, 2 (4.7%)	- Ongoing education of caregivers on emerging patient needs, 14 (25.5%)	
	- Haematological, 2 (4.7%)	<b>Care and logistics:</b>	
	- Infectious, 2 (4.7%)	- Paediatric patients**** 9 (16.4%)	
	- Allergic, 1 (2.3%)	- Human milk donors***** 2 (3.6%)	
	- Nephrological, 1 (2.3%)	- Subcutaneous delivery and management of complications; replacement of infusion systems and removal of PCA, 1 (1.8%)	
		- Administration of subcutaneous drugs to family members, 1 (1.8%)	
		- Delivery of medical reports and prescriptions, 10 (18.2%)	

n, number of patients; PCA, patient-controlled analgesia; SD, standard deviation; % percent over the total of patients included in the study.

\* Human milk bank programme.

\*\* Wound care: surgical wounds, stoma care, cauterisation of granulomas and suture removal.

\*\*\* Telephonic support: followup, answering questions, adherence to treatment, monitoring of symptoms, on demand and scheduled.

\*\*\*\* Provision of supplies to paediatric patients: insulin infusion sets, glucose meters, ketone test strips, etc.

\*\*\*\*\* Human milk donors: equipment and services required for donation of human milk.

Care was delivered either in person (94 visits to 50 patients; 1–9 visits/patient) or remotely (141 contacts with 17 patients, 1–24 contacts/patient) through telephone calls, videoconferencing or electronic mail.

Care was provided during regular working hours, except end-of-life care and bereavement services, delivered 24 hours a day.

There were 8 patients that required a total of 12 hospitalizations in the period under study, with a median length of stay of 6 days (interquartile range, 3.0–8.7). There were also 13 visits to the emergency department, and 2 deaths of patients of the PPCU, both at home. We were not able to compare these data with home-based health care in a previous period.

Although some hospitals in Spain had already set up PHHC services before the pandemic,<sup>1</sup> the transformation of the PPCU into a PHHC team in our hospital stemmed from the need to find immediate solutions during the pandemic to monitor and manage acute and chronic diseases, provide care to the most vulnerable patients and maintain the continuity of care for patients and families<sup>3</sup> while avoiding unnecessary visits to the hospital at a time where the risk of transmission was high. The PHHC team also contributed to maintaining the activity of the human milk bank, all the while avoiding a decline in the care delivered within the scope of the PPCU, such as the support provided to families of patients that die throughout the disease of the patient, the end of life and subsequent bereavement.

Home-based care requires adequate training and a holistic approach to the patient and the family.<sup>1</sup> The pandemic has led to shifts in conventional models of care delivery, and some studies have found that models with a holistic care approach, of which PHHC can be an example, improve patient safety, satisfaction of patients and families, health outcomes and costs, in addition to providing more humane ongoing care.<sup>4–6</sup> The greatest barriers to expanding this model or care to children have been the lack of human resources (such as social workers or physical therapists) and the lack of time.

Promoting and consolidating this model of care requires considerable coordination and communication between specialists, primary care providers and families,<sup>4,6</sup> for which emerging technologies may prove particularly useful.

Our experience has not only helped overcome the limitations of the pandemic, but also to advance our care model toward the future. We believe that the current trend in the care of complex paediatric patients will increasingly approximate the care of adult patients, with a decrease in the frequency of “conventional” hospital stays and a boom in hospital-at-home care, short stay units, palliative care and holistic care programmes, among others.

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## Conflicts of interest

The authors have no conflicts of interest to declare.

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