

EXTENDED SUMMARY

“PEDIATRIC PALLIATIVE CARE: PARENTAL DEMANDS WITHIN THE HEALTHCARE ENVIRONMENT”

AUTHOR: IRENE CHAPARRA RUIZ

INTRODUCTION

Palliative care is defined as the total active care provided by a multi-professional team, belonging to the fields of medicine, nursing, psychology and social work, and It is aimed at patients and their relatives when an illness no longer responds to curative treatments. Thus, its purpose is to preserve the highest possible quality of life during the final disease process, not to extend it (Hutchinson et al., 2003).

Pediatric Palliative Care (CPP) is an emerging specialty of Pediatrics, in constant growth since its origins in the 90s. In spite of sharing the objective of palliation, the strategic line must be different from that followed in the adult field, since the characteristics are not the same in both groups.

OBJECTIVES

General objectives: To acknowledge relatives' demands of pediatric patients with palliative care needs in health care centers.

Specific objectives:

- Exploring parents' complaints and requests about the physical environment and resources provided by the health centre.
- Providing information on parents' demands regarding their presence in pediatric palliative care units.
- Identifying aspects that can be improved in communication of information between health professionals and parents about the disease process of paediatric patients.
- Recognizing the relationship between the specific training of health professionals and the demands of parents in pediatric palliative care contexts.

DESIGN

According to the criteria of the PRISMA Declaration (Urrutia and Bonfill, 2010), this is a systematized bibliographic review (Guirao, 2015).

To elaborate this study we started by exploring the provided material on advanced and end of life disease. Once the topic of pediatric palliative care was selected, the research inquiry was defined and the objectives were settled. After an exhaustive search of specific literature, results were analysed and conclusions were drawn.

Among the inclusion criteria for the selection of the documents that compile this work, a publication date prior to 2012 is found, presented in English or Spanish under the label of research article, systematic review, clinical trial or practical guide. These papers should be categorized within the areas of study that make up the multidisciplinary teams responsible for carrying out paediatric palliative care, discussed above. In addition, participants in these studies are of either sex and age less than or equal to 15 years, which is necessary criteria for belonging to the paediatric field. Additionally, we attempted to ensure that the selected documents have a bibliography that is as well-founded, relevant and innovative as possible.

In light of the conversation within criterias, documents referring to adult palliative care and/or more specific pathologies can be found. These researches, should not be generalized to the whole field, since studies whose summary is not related to the present objective or whose results are not correctly presented are encountered amongst the exclusion criteria.

Through the two bases employed (PubMed, Google Scholar) and combining the different keywords, a total of 167 results were obtained. Whilst evaluating these entries, a total amount of 25 were eliminated because they were duplicated citations. After reading the title and keywords of these documents, 112 were deleted, leaving 31. In addition, further documentation identified from another source was added, in this case, a recommendation from a professional in the field of psycho-oncology. The final number of documents included in this paper is 10.

RESULTS AND CONCLUSIONS

The demands requested by parents can be classified into four major blocks according to: level of their presence, physical environment and resources provided by the health centre, communication with health professionals and training of the latter.

As mentioned in the introduction, the late differentiation between pediatric and adult palliative care is considered the most notorious source of the deficits found (Hutchinson et al., 2003). Therefore, these results in less training of health professionals in this specific field, which in turn, means less self-concept and a greater probability of developing related pathologies (Martínez et al., 2013). However, it has been proven that good training, either during the academic period in the degree or being already incorporated into working life, can mitigate such effects (Schmidt-RioValle et al., 2012).

Within these training programs, one of the elements included should be the communicational and relational aspects, since there is a clear demand on the part of parents and a recognition of complexity on the part of health professionals (Martínez, J.C.D et al., 2012). Likewise, but within this same aspect it is necessary to emphasize the importance of the documents provided by the center (Peng et al., 2017). This is a field not much studied but of great influence in the creation of expectations of the parents of how it is going to be the process of disease that they are going to face (Lima et al., 2019).

The same goes for the physical environment and resources provided by the centre (Fornieles et al., 2019). This is an aspect that, rather than having a negative effect, can act as a protective factor in the situation of creating a home from a hospital room (Butler et al., 2019). Facilities for self-care, rest or privacy and the provision of food are presented as conditioning factors in the role of parents, who come to feel as an active agent in the process that their children experiment (Franchi et al., 2018). Similarly, it is necessary to emphasize that differences are observed between the preference of the parents and recommendation of the professionals, that is, home, and where the process really takes place, the health centre (Martín et al., 2017).

Finally, an increase on the flexibility of timetables and the possibility of being present at surgical operations are also requests made by parents. At the same time, it is necessary to take into account the reasons why these paediatric palliative care units are not fully open and to obtain a balance that mainly looks after the well-being of the patient on a physical and emotional level. Within this aspect, it would be highly recommendable to introduce a

facilitator figure, which has already been implemented in several countries (Butler et al., 2019)

In light of the above exposed, all the selected studies show concordance among themselves and the need for a holistic approach is supported, as there is an interdependency between the aspects studied. With this, the drawn conclusion is that, by meeting the demands of any of the aspects analysed, progress would be made in the rest accordingly.

Practical implications:

- Increased well-being of the three agents involved during the process of the disease, health professionals, relatives and patient, and by extension, of society as a whole.
- Increased understanding and promotion of the holistic vision of palliative care because improvement in any of the four aspects mentioned means progress in the rest accordingly.

Limitations

- Specification of disease in quantity of documents, not located at the general level of pediatric palliative care.
- The evolution of terminology in comparison to previous years may have skewed the search for information in databases.
- Low number of databases used and access denied on certain articles.

Future guidelines

- Parents' needs in non-hospital settings: home as the place where the disease develops.
- Demands by parents of Spanish nationality: differences in terms of the international level.
- Current situation of work-life balance for parents whose child is in a paediatric palliative care unit.
- Distinction in demands of Pediatric Palliative Care Units according to the family model involved.

ABSTRACT

INTRODUCTION: Pediatric Palliative Care (CPP) is aimed at patients under the age of fifteen and their families when a disease no longer responds to curative treatment, so its purpose is no longer to prolong the amount of life but to preserve the highest possible quality during the final disease process. They have different characteristics from those of the adult environment.

OBJECTIVE: The purpose of this paper is to know the demands of the parents of pediatric patients with palliative care needs in health centers.

METHOD: According to the criteria of the PRISMA Declaration, this is a systematized bibliographic review. The inclusion criteria refer to the age of the target subjects, health and social work area, language used, year of publication and document with scientific-empirical character. On the contrary, documents whose content was not related to the specific field of pediatric palliative care and whose bibliography was not correctly presented or innovative have been eliminated.

RESULTS: The demands proposed by the different authors have been collected in four main blocks. The first corresponds to the physical environment of the health centre and would be linked to the role established in these according to the resources provided. The second corresponds to presence and would be associated with the presence or absence of parents in these specialized units as well as in the interventions received by the patients. Thirdly, there are the communication aspects, which are the main demand of parents and are considered by health professionals to be the most complex. Finally, reference is made to the professional training received, proposed as the origin and solution to the deficits found.

CONCLUSION:

All the selected studies show an agreement between them and support the need for a holistic approach. By supplying any demand, progress is achieved in the rest, which shows their interdependence.



INTRODUCCIÓN

Objetivo: calidad de vida ≠ cantidad

Menores 15 años

Diferenciación ámbito adulto

Equipo multidisciplinar

Década 90

Objetivo general: Conocer las demandas de los progenitores de pacientes pediátricos con necesidades de atención paliativa en centro sanitario.

Objetivos específicos

- Explorar las quejas y peticiones de los padres y madres acerca del entorno físico y recursos proporcionados por el centro sanitario.
- Proporcionar información sobre las demandas de los progenitores con lo que respecta a su presencia en las unidades de CPP.
- Identificar aspectos mejorables en la comunicación entre profesionales sanitarios y progenitores sobre el proceso de enfermedad
- Conocer la relación entre la formación específica de los profesionales sanitarios y las demandas de los progenitores en contextos de CPP.

MÉTODO

Se trata de una revisión bibliográfica sistematizada (Guirao, 2015), atendiendo a los criterios de la Declaración PRIMA (Urrutia y Bonfill, 2010).

Criterios de inclusión

- Año de publicación: posterior a 2012.
- Idioma: español o inglés.
- Documentos carácter científico
- Sujetos de sexo indiferente y edad participantes ≤ 15 años.
- Campos de salud y trabajo social.
- Bibliografía relevante y novedosa.

Criterios de exclusión

- Documentos referidos a CP de ámbito adulto y/o patologías más específicas no generalizables.
- Estudios cuyo resumen o conclusión no tuviera relación con el objeto de la revisión o correctamente expresado.

RESULTADOS: categorías extraídas de la revisión de estudios y sus respectivas demandas.

ENTORNO

Importancia del entorno en cualquier fase; especial énfasis en el lugar de fallecimiento.	<i>Fornieles et al., (2019)</i> <i>Hutchinson et al., (2003)</i> <i>Lima et al., (2019)</i>
Servicios actualmente irregulares y erróneamente condicionados.	<i>González et al., (2017)</i> <i>Hutchinson et al., (2003)</i>
Atención en el hogar como prioritaria; preferencia mayoritaria de los progenitores, coincidente con la opinión de los profesionales	<i>Martín et al., (2017)</i> <i>Hutchinson et al., (2003)</i>
Ambiente físico como factor influyente en el desarrollo de colaboración entre progenitores y sanitarios.	<i>Butler et al., (2019)</i>
Instalaciones para el autocuidado, descanso o privacidad y suministro de alimentación como factores condicionantes en el rol de los progenitores.	<i>Butler et al., (2019)</i> <i>Franchi et al., (2018)</i> <i>Lima et al., (2019)</i>
Posibilidad de personalización como factor protector.	<i>Butler et al., (2019)</i>

PRESENCIA

Deseo de elección durante determinadas intervenciones.	<i>Butler et al., (2019)</i> <i>Franchi et al., (2018)</i>
Petición de una mayor flexibilidad en cuanto a horarios.	

Fuente: elaboración propia.

COMUNICACIÓN

Constante demanda de un trato más humanizado por parte del personal sanitario	<i>Franchi et al., (2018)</i> <i>Martín et al., (2017)</i> <i>Peng et al., (2017)</i> <i>Schmidt-RioValle et al., (2012)</i>
Petición de un aumento de la transmisión de información y de una manera más natural, empática y comprensiva.	<i>Butler et al., (2019)</i>
Aspectos comunicacionales como los de mayor complejidad.	<i>Martínez, J. C. D et al., (2012)</i>
Influencia de la información recogida en los documentos proporcionados; creación de expectativas a través del lenguaje empleado.	<i>Fornieles et al., (2019)</i> <i>Martín et al., (2017)</i> <i>Lima et al., (2019)</i> <i>Peng et al., (2017)</i>

FORMACIÓN

Tardío reconocimiento de necesidades específicas en CPP como origen-solución	<i>Hutchinson et al., (2003)</i> <i>Martínez, J. C. D et al., (2012)</i>
Educación específica	<i>Martínez et al., (2013)</i> <i>Peng et al., (2017)</i> <i>Schmidt-RioValle et al., (2012)</i>
Nivel disminuido de autoconcepto en los profesionales.	<i>Martín et al., (2017)</i> <i>Martínez et al., (2013)</i>

Proceso del estudio y diagrama de flujo



CONCLUSIÓN

Implicaciones prácticas

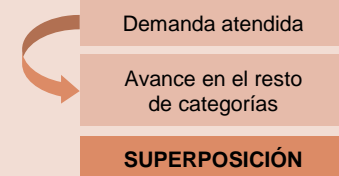
- Incremento del bienestar en los tres agentes implicados
- Fomento de la investigación de forma holística

Limitaciones

- Especificación de enfermedad en cantidad de documentos,
- La evolución de la terminología con respecto a años anteriores
- Bajo número de bases de datos utilizadas y acceso denegado en determinados artículos.

Directrices futuras

- Necesidades de los progenitores en un ambiente no hospitalario: hogar como lugar del proceso de enfermedad.
- Demandas por parte de padres y madres de nacionalidad española: diferencias con respecto al plano internacional.
- Situación actual de la conciliación laboral de progenitores cuyo hijo/a se encuentra en una unidad de CPP.
- Distinción de las demandas en las unidades de CPP según el modelo de familia involucrado



REFERENCIAS BIBLIOGRÁFICAS

Butler, A. E., Copnell, B., & Hall, H. (2019). The impact of the social and physical environments on parent–healthcare provider relationships when a child dies in PICU: Findings from a grounded theory study. *Intensive and Critical Care Nursing*, 50, 28-35.

Fornieles, M. P., Barbero, P. G. M., Miñarro, A. M. G., Barbieri, G., Bellavia, N., Cortés, M. D. M. B., & Mingorance, Á. N. (2019, August, In Press). Eficacia del Equipo de Cuidados Paliativos Pediátricos de Murcia según la experiencia de los padres. *Anales de Pediatría*. Elsevier Doyma. DOI: 10.1016/j.anpedi.2019.07.001

Dolan, P. and Shaw, R. and Tsuchiya, A. and Williams, A. (2004) QALY maximisation and people's preferences: a methodological review of the literature. *Health Economics* 14(2):pp. 197-208.

Franchi, R., Idiarte, L., Darrigol, J., Pereira, L., Suárez, R., Mastropiero, L., & Fernández, A. (2018). Unidad de cuidados intensivos pediátricos de puertas abiertas: experiencia y opinión de los padres. *Archivos de Pediatría del Uruguay*, 89(3), 165-170.

Guirao Goris, S. J. A. (2015). Utilidad y tipos de revisión de literatura. *Ene*, 9(2), 0-0.

Hutchinson, F., King, N., & Hain, R. D. W. (2003). Terminal care in paediatrics: where we are now. *Postgraduate medical journal*, 79(936), 566-568.

Lima, K. M. D. A., Maia, A. H. N., & Nascimento, I. R. C. D. (2019). Comunicación de malas noticias en cuidados paliativos en la oncopediatria. *Revista Bioética*, 27(4), 719-727.

Martín, J. A., Rodríguez, I. M., Párraga, M., Campos, A., & Cabrera, A. (2017). Situación actual de la prestación de los cuidados paliativos pediátricos en España. *Calidad de vida, cuidadores e intervención para la mejora de la salud*, 71-77.

Martínez, J. C. D., De Miguel, C., Morillo, E., Noguera, A., Portela, B. N., & López, D. R. (2012). Discurso de los profesionales de cuidados paliativos de la Comunidad de Madrid sobre la atención psicológica. *Psicooncología: investigación y clínica biopsicosocial en oncología*, 9(2), 467-481.

Martínez, P. V., & Salvador, I. G. (2013). Formación básica en cuidados paliativos: estado actual en las universidades de enfermería españolas. *Medicina Paliativa*, 20(3), 111-114.

Peng, N. H., Lee, C. H., Lee, M. C., Huang, L. C., Chang, Y. C., & DeSwarte-Wallace, J. (2017). Effectiveness of pediatric palliative care education on pediatric clinicians. *Western journal of nursing research*, 39(12), 1624-1638.

Schmidt-RioValle, J., Montoya-Juarez, R., Campos-Calderon, C. P., Garcia-Caro, M. P., Prados-Peña, D., & Cruz-Quintana, F. (2012). Efectos de un programa de formación en cuidados paliativos sobre el afrontamiento de la muerte. *Medicina paliativa*, 19(3), 113-120.

Serrano Font, M. (2017). *Más allá de la comunicación: Procesos de Advance Care Planning (toma de decisiones y planificación adelantada) en cuidados al final de la vida* (Doctoral dissertation, Universitat Jaume I, Castellón, España).

Urrútia, G., & Bonfill, X. (2010). Declaración PRISMA: una propuesta para mejorar la publicación de revisiones sistemáticas y metaanálisis. *Medicina clínica*, 135(11), 507-511.