

Paediatric Palliative Care Workers- A Qualitative Investigation by a Home-Based Multidisciplinary Healthcare Group

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Abstract

Compassion fatigue affects healthcare professionals who treat youngsters with life-threatening illnesses. This study set out to illustrate how members of an interdisciplinary paediatric palliative home care team felt and how they reacted to certain situations. A qualitative case study with 18 individuals was carried out. The home-based, multidisciplinary paediatric palliative team was part of the deliberate sampling technique approach. Semi-structured interviews and the field notes of the researchers were used to gather the data. There was a theme analysis. Two themes emerged; improving life, which explained how professionals value life more and how helping children and families gives them a sense of fulfilment from their compassion, which affect their job satisfaction and may lead to burnout, showing how experiencing in-hospital child detention can have an adverse effect on job satisfaction. Our study describes potential reasons why professionals caring for kids with life-threatening illnesses experience emotional discomfort and recommends techniques that can help them feel less distressed.

Keywords: Healthcare; Palliative care; Paediatrics; End of life; Patients

Introduction

PPC (paediatric palliative care) addresses the needs of children and adolescents with serious medical conditions, serious injuries, or both [1,2]. In difficult or urgent cases involving end-of-life care and grief after the child has passed away, individuals who are part of the multidisciplinary PPC department (ID-PPC) are responsible for identifying the goals of care, controlling symptoms, and helping decision-making. They are additionally responsible for protecting the kid and family from harm and minimising pain. ID-PPC professionals regularly encounter emotionally challenging clinical environments [3,4]. These interactions are more prolonged in PPC compared to adult palliative care because of the longer care durations [5]; thus result, the bonds among patients and their loved ones are strengthened, and the mental workload of the doctor increases. Additionally, as a health practitioner, experiencing a child's death is more upsetting and painful than doing so with an adult [6,7]. Healthcare practitioners personal health and work performance can be affected by all three phenomena of compassion fatigue, burnout, and compassion satisfaction. Compassion fatigue is the emotional anguish that professionals endure as a result of ongoing exposure to patients' suffering and results from having empathy for the afflicted individual [8]. Burnout is a phenomenon that leads to professional discontent and is characterised by emotional weariness, depersonalization towards patients, and a diminished sense of personal fulfilment [9]. The emotional gratification gained from helping others is known as compassion satisfaction [10]. In-patient PPC practitioners exhibit low levels of compassion fatigue and burnout along with elevated rates of job satisfaction, according to the limited research that have been conducted on the topic [11-13]. A greater knowledge providing the realities and consequences of this type of work is necessary, as the overall fulfilment of specialists looks to be a crucial factor in the effectiveness and quality of palliative care. By doing the execution specific survey forms or by examining their general experiences with giving PPC at the conclusion of life via qualitative investigations [14], previous investigations.

Materials and Methods

A comprehensive case investigation was created. This structure

makes it possible to investigate complicated events in their actual context and to gather data from many sources (different professions). This approach includes many people, situations, locations, and times that are linked by the phenomenon being studied. The manner of caring for the children participating in the Madrid PPC programme as it was perceived by the many specialists that operate in their homes ID-PPC constituted the phenomenon in this study. The primary trait of qualitative case studies is that they offer a thorough investigation of the unit under study, which might be a person, an organisation, an organisation, or as in this instance the ID-PPC of Madrid [15-20]. The sole specialised PPC Unit in this town, which is now housed at the Nio Jesus Hospital, provides PPC in Madrid at this time. Each year, the Nio Jess Hospital's specialised PPC Unit sees about 220 new paediatric patients. Its primary focus is on children's homes, where it attends to about 180 episodes of in-home hospitalisation each year and provides palliative care to about 90 kids there. At least 8% of the 2,000 home visits conducted each year are for continuous care, and 24-hour care is offered. 30 percent of the youngsters seen had oncological disorders, and 70 percent have neurological diseases. To include participants who had knowledge that was pertinent to the investigation, snowball and purposeful sampling strategies were used. All professionals who took part in the home-based ID-PPC were included in the study sample. In qualitative research where it is possible to have access to all participants with pertinent knowledge on the case study, it is advised to include all participants. Professionals engaged in home-based ID-PPC were studied. Becoming an affiliate of the ID-PPC and providing home care at the time of the study was the only requirement for enrollment. Specialists in medical palliative medicine, trained Hospice nursing,

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specialist palliative care psychology, trained hospice care social services, professionals supportive care physiotherapy, and specialist palliative care administrative staff were among the professionals who complied with the a home-based ID-PPC. The informed consent form was submitted for signature by each participant.

Analysis

Each interview was transcription, along with researcher notes. Three researchers (PRM, JGR, and DPC) examined the transcribed texts using an inductive thematic analysis. The coding and topic identification process involved reading the entire book, going paragraph by paragraph, and performing a thorough line-by-line examination. The coding process was divided into several stages:

- The first codes were produced.
- Following that, codes were put into categories. Following the grouping of the categories, themes and sub-themes were determined.
- Following a study of the themes, additional themes were discovered, their conceptual maps were created, and the themes were recoded.
- Themes and sub-themes were identified and defined, creating their definition.

Results

This study included 18 individuals (12 women and 6 males). The home-based ID-PPC participants had an average age of 38.2 years. These included one non-health employee (5.6%, administrative services personnel), other health professionals (16.7%, psychologists and physiotherapists), non-health professionals (11.1%, social workers), and paediatricians who made up 38.9% of the group. Nurses made up 27.8% of the group. The average tenure of the professionals at the at-home ID-PPC was 6.0 3.4 years. Our findings demonstrated how caring for these kids can impact job satisfaction and burnout among clinicians who provide paediatric palliative care, including end-of-life care. Understanding the psychological effects of palliative care work aids in better understanding the idea of PPC and how it is provided by experts. The at-home ID-PPC specialists considered the advantages that their commitment to PPC affords them, including the capacity to make more sense of life, emotions related to personal progress, fulfilment, depth of knowledge, and a more sympathetic approach to clinical care. Practitioners are encouraged to adopt a new perspective and a more optimistic understanding of life through caring for children and families in the palliative context. They claimed that modifications in their priorities and life objectives had aided in their development as individuals. They also talked about how their PPC experience had aided in their professional growth.

Discussion

Our findings highlighted personal development and compassion fulfilment by demonstrating how professionals committed to giving PPC experienced good feelings and emotions while providing care. Even while they described their work as calming, they agreed that it often had a significant emotional impact, which was made worse by witnessing terrible deaths. According to the essential elements of personal growth outlined by Tedeschi and Calhoun in five domains, our participants demonstrated improvements in their personal resources and relationships, as well as positive changes in their priorities and aspirations in life, as well as a higher appreciation for life. Beaune et al. demonstrated how, despite not being members of

an ID-PPC, physicians, social workers, and nurses underwent personal growth, had a greater appreciation for their blessings, and became more compassionate when caring for children with life-limiting illnesses. In our participants, benevolence appeared to play a role in their sense of personal progress. It is defined as an altruistic and caring attitude associated to the desire to enhance patient care and has been recognised as a positive consequence of care. The nurses in Conte's research discussed how their work in paediatric oncology had taught them to value their lives and the time they spend with loved ones more. Professionals also highlighted how working in PPC made them a "better professional". The Morrison and Morris study's bone marrow transplant unit nurses highlighted potential in developing new technical skills, learning about specific diseases, and being enriched by daily patient-centered rounds with an interdisciplinary team. They felt fortunate to care for children through what they perceived to be the most difficult moment of their life, much like our participants did. Prior research also found high levels of work satisfaction among PPC specialists, which is consistent with our findings. Less research has been done on satisfaction and compassion fatigue in healthcare professionals. On the other side, there is a lot of data supporting burnout. However, among the 150 PPC providers that took part in a study in the US in 2019 burnout (12%) was less common than compassion fulfilment (25%) and compassion weariness (18%). Promoting compassion fulfilment is crucial, rather than merely preventing or reducing compassion fatigue or professional burnout. Kase et al. found that physical tiredness, a personal history of trauma, recurrent engagement in a clinical setting in which life-prolonging treatments were not implemented, and failure to confront heavy concerns were predicted variables for lower compassion satisfaction levels. According to our findings, close relationships with families, open communication, and teamwork within the team are all factors that reinforce compassion satisfaction. Personal experiences of illness or suffering in the private lives of ID-PPC professionals also increased their empathy and reduced their physical exhaustion. Klassen et al. came to the conclusion that one of the major benefits experienced by paediatric oncology specialists was their ability to build strong bonds with parents and support families throughout the entire oncology procedure, including PPC. The medical experts also talked about how they suffered and felt morally and emotionally uncomfortable when life-prolonging techniques were employed on patients without putting their wellbeing first. Our findings therefore showed that, rather than lower rates as reported by Kase et al., the involvement of the ID-PPC in clinical settings where burdensome life-prolonging treatments are not adopted was connected to a better satisfaction with the experts' compassion. Our research revealed three factors that may contribute to PPC professionals' high levels of job satisfaction: (1) the humanization of care during the child's illness and death; (2) a sense of honour and satisfaction at being able to support parents during the challenging process of coping with the illness and death of their children; and (3) the fact that PPC allows the child to live at home rather than in a hospital. The emotional load of caring for children with life-limiting/life-threatening diseases appeared to be easier to handle for ID-PPC professionals providing home care when they were happy with their work. The participants' admission of having a demanding and mentally taxing work that leaves them with "emotional scars" was consistent with earlier research. Distress over the clinical condition, physical tiredness, and personal loss were listed as three predictors of compassion fatigue among PPC professionals by Kase et al. In our study, a link between physical tiredness and the dynamism of home care and 24-hour care also appeared. Additionally, personal loss was not identified in our results, but similar personal circumstances related to the emotion of loss were, such as the professionals decision to have a child and to

empathise with the families who have lost a loved one, which they believe may make them weak and prevent them from performing their duties. As a result of care, but not just in the palliative setting, negative emotions and sentiments like grief, agony, sadness, and suffering also surfaced. The experts claimed that cancer or paediatric critical care units were where bad deaths were most painfully experienced outside of palliative care. PPC places a lot of emphasis on the idea of a good death. Less research has been done on what constitutes a "good death" for children than for adults, and the studies that have been done on this topic have all dealt with kids who have cancer.

Our work contributes to filling this knowledge gap by providing pertinent information, drawing on the expertise of the most specialised practitioners in paediatric end-of-life care, and putting light on variables and traits that may lead to a bad death for kids and their families. In line with the anguish and discomfort experienced by the professionals in our study, Lee and Dupree also noted that the major psychological reactions of critical care staff when caring for a dying infant were sadness and grief as opposed to moral distress. When institutional restrictions keep you from acting morally righteously despite knowing what to do, moral discomfort results. Although moral distress is a prevalent emotion in paediatric and neonatal ICUs, a research by Dryden-Palmer et al. found that it is also linked to higher depersonalization of care and confusion around end-of-life decision-making in a child's life. Additionally, the emotional support provided to employees in paediatric critical care units is insufficient to help them deal with the sadness of losing infants.

Our findings demonstrated how the experience of "bad deaths" in other professions, such as oncology or paediatric intensive care, seems to influence professionals to develop an interest in PPC and give up intensive care, as was the case with three of the seven doctors and four of the five nurses who took part in the study. The nurses from Maytum et al.'s qualitative study who were committed to caring for chronically ill children, like our participants, described strategies that reduced episodes of compassion fatigue and were helpful for preventing burnout: picking a work environment in line with their personal philosophy, changing jobs when necessary, or taking advanced training courses. The assistance given by ID-PPC to other paediatric services working with critically sick children is essential to preventing professional anguish and burnout, according to Jonas and Bogetz. Among American neonatologists, Weintraub et al. found that PPC usage was a predictor of higher compassion satisfaction. Professionals consider that feeling sorrow and grief at the death of the kid demonstrates humanity and a connection to the child and family. According to prior suggestions to minimise weariness and burnout, our results highlighted various techniques incorporated into the home-based ID-PPC performance: peer support, honest communication, family life, and team meetings following challenging clinical circumstances. Professionals can also relax with a sense of humour, optimistic outlook, and time away from the office. These elements aid in explaining the increased satisfaction levels observed by PPC specialists. The European Atlas of Palliative Care expresses the necessity for continued development of PPC, which is presented in this study as an essential viewpoint from our geographic area. This is, as far as we are aware, the only study that has particularly looked at the thoughts and sentiments of professionals associated with a specialised ID-PPC in Spain. Additionally, it significantly adds to the body of literature already in existence, which is mostly devoted to paediatric oncology or end-of-life care. The majority of previous studies mostly focused on the experiences of doctors, nurses, and social workers in PPC, but our research also included psychologists, physiotherapists, and administrative personnel as well as the perspective of the ID-PPC.

Conclusion

Understanding the emotional impact of ID-PPC professionals who work from home helps one comprehend the significance and scope of PPC. The quality of PPC may be raised by including the opinions of ID-PPC professionals to help adopt strategies that reduce professional stress and burnout and support their wellbeing.

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Not applicable.

Conflict of Interest

Author declares no conflict of interest.

References

1. Chambers L (2018) A guide to children's palliative care. Supporting Babies, Children and Young People with Life-Limiting and Life-Threatening Conditions and Their Families.
2. Benini F, Papadatou D, Bernada M, Craig F, De Zen L, et al. (2022) International Standards for Pediatric Palliative Care: From IMPaCCT to GO-PPaCS. *J Pain Symptom Manag* 63:529-543.
3. Kase SM, Waldman ED, Weintraub AS (2019) A Cross-Sectional Pilot Study of Compassion Fatigue, Burnout, and Compassion Satisfaction in Pediatric Palliative Care Providers in the United States. *Palliat Support Care* 17:269-275.
4. Rourke MT (2007) Compassion Fatigue in Pediatric Palliative Care Providers. *Pediatr Clin N Am* 54:631-644.
5. Groh G, Feddersen B, Führer M, Domenico Borasio G (2014) Specialized Home Palliative Care for Adults and Children: Differences and Similarities. *J Palliat Med* 17:803-810.
6. Jonas D, Scanlon C, Rusch R, Ito J, Joselow M (2018) Bereavement After a Child's Death. *Child Adolesc Psychiatr Clin N Am* 27:579-590.
7. Huggard P, Law J, Newcombe D (2017) A systematic review exploring the presence of vicarious trauma, compassion fatigue, and secondary traumatic stress in alcohol and other drug clinicians.
8. Maslach C, Jackson SE (1981) The Measurement of Experienced Burnout. *J Organ Behav* 2:99-113.
9. Stamm B (2002) Measuring Compassion Satisfaction as Well as Fatigue: Developmental History of the Compassion Satisfaction and Fatigue Test. New York, NY, USA.
10. Korones DN (2007) Pediatric Palliative Care. *Pediatr Rev* 28:46-56.
11. Korzeniewska-Eksterowicz A, Przysło Ł, Grzelewski T, Stolarska M, Młynarski W, et al. (2010) Job Satisfaction among Health Professionals of Home Hospice for Children of Lodz Region. *Adv Palliat Med* 9:67-72.
12. Liben S, Papadatou D, Wolfe J (2008) Paediatric Palliative Care: Challenges and Emerging Ideas. *Lancet* 371:852-864.
13. McConnell T, Porter S (2017) The Experience of Providing End of Life Care at a Children's Hospice: A Qualitative Study. *BMC Palliat Care* 16:1-6.
14. Tong A, Sainsbury P, Craig J (2007) Consolidated Criteria for Reporting Qualitative Research (COREQ): A 32-Item Checklist for Interviews and Focus Groups. *Int J Qual Health Care* 19:349-357.
15. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA (2014) Standards for Reporting Qualitative Research: A Synthesis of Recommendations. *Acad Med* 89:1245-1251.
16. Sgourakis G, Gockel I, Karaliotas C, Moehler M, Schimanski CC, et al. (2012) Survival after chemotherapy and/or radiotherapy versus self-expanding metal stent insertion in the setting of inoperable esophageal cancer: a case-control study. *BMC Cancer* 12:70.
17. Stahl M, Budach W, Meyer HJ, Cervantes A (2010) Esophageal cancer: Clinical Practice Guidelines for diagnosis, treatment and follow-up. *Ann Oncol* 21:46-49.
18. Christie NA, Buenaventura PO, Fernando HC, Nguyen NT, Weigel TL, et al. (2001) Results of expandable metal stents for malignant esophageal obstruction in 100 patients: short-term and long-term follow-up. *Ann Thorac Surg* 71(6):1797-1801.

19. Conio M, Repici A, Battaglia G, De Pretis G, Ghezzo L, et al. (2007) A randomized prospective comparison of self-expandable plastic stents and partially covered self-expandable metal stents in the palliation of malignant esophageal dysphagia. *Am J Gastroenterol* 102(12):2667-2677.
20. Lightdale CJ, Heier SK, Marcon NE, McCaughan JS Jr, Gerdes H, et al. (1995) Photodynamic therapy with porfimer sodium versus thermal ablation therapy with Nd:YAG laser for palliation of esophageal cancer: a multicenter randomized trial. *Gastrointest Endosc* 42:507-512.