Exploring general practitioners' perspectives on their involvement in pediatric palliative care – a qualitative study

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Abstract

Background: Pediatric palliative care aims to provide holistic support to children with life-limiting conditions and their families. In Belgium, specialist doctors and palliative liaison teams coordinate pediatric palliative care, yet the role of general practitioners (GPs) in this process remains unclear. Given their accessibility, long-term relationships with families, and potential to ensure continuity of care, GPs could play a crucial role in pediatric palliative care.

Aim: This study explores the perspectives of GPs in Flanders, Belgium, regarding their role, needs, and barriers in pediatric palliative care, and identifies opportunities to enhance their involvement.

Methods: Semi-structured interviews were conducted with ten GPs from both rural and urban areas of Flanders. The interviews were transcribed verbatim and analyzed thematically.

Results: While only one GP had direct experience with pediatric palliative care, most expressed a willingness to engage. Five perceived roles emerged: being involved by default, providing accessible and trusted care, utilizing long-term family relationships, coordinating care among providers and lastly, delivering generalist pediatric palliative care within defined limits. Key barriers included limited pediatric palliative care-specific knowledge, lack of structured communication with specialists, and insufficient integration into pediatric palliative care pathways. GPs emphasized the need for earlier involvement, improved communication channels, and structured support from specialized pediatric palliative care teams.

Conclusion: GPs in Flanders may be willing yet underutilized contributors to pediatric palliative care. Their accessibility, continuity and holistic approach suggest potential to effectively support children and families, provided they receive clearer communication and structured specialist support. Enhancing GP involvement could improve the delivery of pediatric palliative care in community settings.

Keywords: pediatric palliative care, general practitioners, qualitative research, care coordination, Belgium

Title

Exploring general practitioners' perspectives on their involvement in pediatric palliative care – a qualitative study.

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1. Background

1.1 Definition and scope of pediatric palliative care

Pediatric palliative care is a holistic approach to the care of children living with life-limiting or life-threatening conditions. The World Health Organization (WHO) has given the following definition for pediatric palliative care: *the active total care of the child's body, mind and spirit, and also involves giving support to the family.* Pediatric palliative care *begins when a child is diagnosed with a disease and continues regardless of whether the child receives treatment. Healthcare providers' task consists of evaluating and alleviating a child's physical, psychological, and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources. It can be provided in tertiary care facilities, in community health centers and even in children's homes* (1).

A recent study of Connor et al. (2017) estimated that there are more than 21 million children worldwide that are in need of palliative care (2). Studies estimate that 20 to 66 per 10,000 children are affected by life-limiting conditions which require pediatric palliative care (3–5). Fraser et al. (2020) found the prevalence of life-limiting conditions in children to be steadily climbing, with most pathologies being congenital abnormalities, followed by neurological conditions such as cerebral palsy and neurometabolic diseases (4).

Since the 1980's there has been an increasing interest in pediatric palliative care worldwide, as demonstrated by the ever-growing number of studies that are being published on the subject. While most of the earlier studies focused on developing practice guidelines, education of health professionals and the accessibility of pediatric palliative care services, from 2010 onward, the focus seems to have shifted more toward the experience of the patient and their family, as well as the bereavement phase (both before and after the death of the patient) (6,7).

1.2 General practitioners and (adult) palliative care

Even though GPs do not often encounter pediatric palliative care in their daily practice, it is important that they are able to deliver pediatric palliative care, given the significance of this life stage for patients and their caregivers. This is why it is important to promote the education of healthcare providers on these clinical guidelines and to continue research on the topic. The involvement of GPs in adult palliative care has already proven to be a valuable component of adult palliative care (8–10). GPs are primary healthcare providers who maintain long-standing relationships with patients and their families. One of their major strengths is that they are capable to provide ongoing care for their patients and their respective families within their communities, even at home if necessary (11,12). This makes

palliative care at home more feasible, which is of utmost importance considering that most patients prefer to be cared for and to die at home (8). GP home visits have been positively associated with facilitating home death (9). Furthermore, dying at home seems to be positively associated with a higher likelihood that bereaved relatives evaluate the palliative trajectory as successful (12). Johnson et al. (2018) recently performed a systematic review with the intent to explore patient and carer expectations regarding the role of GPs at the end of life in adult palliative care, as well as investigating the role of GPs in advance care planning for these patients. Three recurring themes were prominent when it came to patient and carer expectations: competent and effective symptom relief, open communication, and availability of the GP, particularly when the patient's health further deteriorates (9). Research also shows that the long-term relationship between patient and GP also facilitates the process of advance care planning (i.e., discussing and preparing for future decisions about your medical care if you become seriously ill or unable to communicate your wishes) (13,14). This may be especially important for non-cancer patients with palliative care needs who are less likely to receive specialist palliative care than cancer patients and who are thus more likely to rely on their GP for palliative care (15,16).

Specialized versus generalist palliative care

Specialized palliative care is provided by a specialized multidisciplinary team and covers the more complex aspects and problems of palliative care. Generalist palliative care is given by GPs and other health care providers and deals with the more basic aspects of palliative care such as treating common symptoms such as pain and nausea. Despite the rare occurrence of pediatric palliative care in GP practice, it is important to emphasize that knowledge and awareness of this can be of great value to the patient and their caregivers, given how important this stage of life is (22–24). Seeing as the need for palliative care keeps rising, and a trend to shift from institutionalized palliative care to community-oriented palliative care takes place, the need for GPs in palliative care delivery will keep increasing (25). Specialized palliative care alone cannot deliver the needed capacity to provide care to the growing population in need of palliative care, nor does every palliative patient require specialized palliative care (26).

1.3 General practitioners and pediatric palliative care

While the role of the GP in adult palliative care is getting better established and specialized pediatric palliative care continues to expand, the role of GPs in the process of pediatric palliative support remains less clearly defined (17,18). Studies about parents' expectations vis-à-vis GPs roles at the end of life of their child are limited, as well as studies on the perspectives of general practitioners on their involvement in pediatric palliative care.

Although clinical guidelines for pediatric palliative care exist, their implementation in practice is often inadequate. This is primarily due to a lack of empirical evidence underpinning the guidelines as well as the limited clinical exposure of healthcare providers to pediatric palliative cases (6,19–21). For example, a study by Neilson et al. (2017) in the United Kingdom reported that most general practitioners acknowledged unfamiliarity with pediatric medication doses and found it difficult to keep up to date with standards, given the rarity of such cases (22). Similarly, Straatman et al. (2015) in Canada found that only 32.6% of surveyed GPs felt their knowledge of pediatric palliative care was adequate (23).

Yet, involving GPs in pediatric palliative care may benefit children with palliative care needs and their families. Most families prefer that the affected child receives palliative care , which can be facilitated by GPs. This allows for more privacy, to be more surrounded by family and loved ones and it gives the parents and children an increased authority over the management of care (24,25). Nevertheless, the choice of care location remains personal, and some parents, for instance, prefer a more controlled environment close to the treatment team (26). As mentioned before, GPs are easily accessible and approachable which helps establish a strong, ongoing relationship, while also offering long-term care to patients. Van der Geest et al. (2014) found good communication between parents and health care professionals, continuity of care and parental involvement in decision making regarding their child's palliative care treatment to be important factors in parents' perception and experience with pediatric palliative care, with the first two positively affecting the levels of long-term parental grief (27). Even after the death of the patient, there might be a possible role for GPs, as they can guide support and follow-up of parents and siblings, with referral to other sources of support if needed.

The involvement of GPs in pediatric palliative care is not part of routine GP practice, and preferences regarding their involvement in pediatric palliative care may vary among practitioners. Neilson et al. (2011) described how the rarity of such cases in GP practice, as well as the fact that initiation of pediatric palliative care usually starts in-hospital, often resulted in GPs not being included in the first phases of pediatric palliative care. In this study, GPs expressed that they felt that 'the child disappeared into the system', and that they found it hard to keep in contact with the patient and their family (28). Some GPs may recognize it as an integral part of their professional responsibilities and an opportunity

to provide support to children affected by serious illness and their families, while others may deem it unfeasible due to time restraints and lack of knowledge on the subject (22). The provision of palliative care for children presents multiple challenges and complexities, including the need for specialized knowledge, communication skills, ethical dilemmas, psychosocial support, time pressure, the difficulty of navigating healthcare systems and involving the child itself regarding their own care planning (29–31). Consequently, GPs may face uncertainties and apprehensions regarding their role in pediatric palliative care.

A recent study conducted in the Netherlands investigating the perspectives of GPs who cared for children with incurable cancer in a home-based setting indicated that difficulties with communication and cooperation among healthcare professionals were rare and that most of the GPs were content with the level of care they were able to provide. About half of the GPs were found to be thoroughly affected by the child's death, with more than 90% coming to terms with the patient's death in the end (32). Unfortunately, auxiliary studies about the experiences of GPs in pediatric palliative care are scarce, with none of them carried out in Belgium (23,28,32,33).

1.4 The pediatric palliative care system in Belgium

When we look at our national health system, Belgium has a relatively advanced specialized pediatric palliative care system with six pediatric palliative liaison teams, all tied to the Belgian Pediatric Palliative Care group. The goals of these liaison teams are to support children with palliative care needs intrahospital and their treating physicians, as well as providing continuity of care at home, ensuring full-time connection with the treating medical team in hospital (34). The necessity of this continuity of care was further described in a Royal Decree in 2010, stating that continuity of care should be available for all both in- and out-hospital patients with serious illnesses (35). In the model made by the palliative liaison teams, the family is seen as the central point, not the pathology of the child with palliative needs. The tasks of these liaison teams include, but are not limited to, organizing and coordinating care of the child and their families, improving communication between health care providers and the child and their families and making sure advance care planning is conducted. The palliative liaison teams' view aims to have pediatricians, (home) nurses and GPs collaborate to ensure continuity of care (34). There are however certain difficulties that hinder the palliative liaison teams in performing their tasks. For example, there were cases where the palliative liaison team had trouble coordinating palliative care due to families not having a designated GP. The system of coordinating pediatric palliative care initially originated from oncology wards and was funded by 'Kom op tegen Kanker', a cancer research fund, which might explain why up to this day cancer patients make up the largest group of their patient population. This stands in stark contrast to the fact that children living with life limiting conditions, hence children in need of palliative care, are more often affected by neurological

diseases than by cancer.(36). No studies were found which described how well GPs manage to consult the children's treating specialists or the palliative liaison team when needed, nor were studies found on how GPs experience their own role in pediatric palliative care in Belgium.

2. Research questions

The main aim of this study is to explore the perspectives of GPs in Flanders on their role and involvement in pediatric palliative care.

More specifically, this study aims to answer the following research questions:

1) What are the perspectives of GPs regarding their role in pediatric palliative care?
2) What are their motivations, concerns, and support needs regarding their involvement in pediatric palliative care?
3) What are possible barriers and opportunities for enhancing the engagement of GPs in Flanders with pediatric palliative care?

3. Methodology

3.1 Study design

This is a qualitative semi-structured interview study with general practitioners.

3.2 Setting

The study took place in general practices in Flanders, Belgium (Brussels included).

3.3 Participants

We aimed to include general practitioners, meeting the following eligibility criteria:

Inclusion criteria:

- Practicing as a GP, and being licensed in the region of Flanders (Brussels included).

Exclusion criteria:

- Unable to understand and speak Dutch or English.

3.4 Recruitment procedures

An e-mail was sent to the GP Societies (or so called '*Huisartsenkringen')* of Flanders and Brussels. These are associations that group all voluntarily joined GPs who practice their professional activity within a certain GP zone. A GP zone is defined as a contiguous geographic area of one or more municipalities,

or part of a municipality in the major agglomerations. This e-mail served as our recruitment mail and consisted of the following: a short explanation of the aim of the study, the methodology (how the interviews will be carried out and analyzed) and the contact details of the principal researcher. The GPs Societies were asked to forward the recruitment e-mail to the active GPs in their region. This way, we hoped to reach GPs in different parts of Flanders and Brussels, as well as diversify our interviewees' age- and gender. We aimed to recruit ten GPs. GPs who were willing to participate could then contact the interviewer by e-mail or phone and disclose their contact details. Then the principal researcher contacted the interested GPs by phone or e-mail to give them more detailed information about the aim of the study and the data collection procedure. When they were still interested in participating after having received this information, the researcher made an appointment to conduct the interview at a time and location of their choosing face-to-face, or online (in a secure end-to-end encrypted Microsoft Teams meeting) if preferred by the interviewee.

3.5 Informed consent and data collection procedure

Before the start of the interview, the purpose of the study was once again explained to the participant. Afterwards, they were asked to read and sign the informed consent form in which they agreed to participate in the interview, gave permission to record the interview and to use their pseudonymized interview data for the study. Any questions concerning the study or data collection could be posed to the researcher who performed the interview. Before the start of the interview, the interviewee was informed that they could pause or stop the interview at any time. In case a problem or question arose after the interview, the participants could contact the researcher via the contact information found in the informed consent document.

GPs were interviewed either face to face or online (in a secure end-to-end encrypted Microsoft Teams meeting) if preferred by the interviewee. The interview took place at a time and location of their choosing (or online as stated above) and the audio was recorded. A classic audio recorder (otherwise known as a digital voice recorder) was used for the recording of the face-to-face interviews, for online interviews the Microsoft Teams application was used to record the audio. The topic guide to the interviews can be found in Annex 1.

3.6 Data analysis and integration

Each interview was audio-recorded and transcribed verbatim. Thematic analysis was used to analyze the transcribed interviews. This qualitative method allows for the systematic identification, organization, and interpretation of patterns (or themes) within the data, providing a detailed account of participants' experiences and perspectives.

This process starts with the primary researcher familiarizing himself with the data, followed by coding data to identify meaningful data segments. These codes were subsequently grouped into broader themes that capture recurring ideas and narrative from across our dataset. The data within the generated themes need to cohere together meaningfully and different themes should have clear and identifiable distinctions between them. If the themes didn't adhere to these criteria, they were iteratively refined until they did. This approach provides a nuanced understanding of the research topic, enabling an in-depth exploration of the participants' shared and divergent experiences. (37) Said data analysis was performed using MaxQDA.

3.7 Data management

All the gathered data were stored on SharePoint, the secure central network drive of the Vrije Universiteit Brussel. It is only accessible via a login and password by the researchers involved in the study. After the end of the study, the dataset is stored in the VUB archive for 10 years.

3.8 Ethics

The study protocol was submitted to the Medical Ethical Commission of UZ Brussel and was approved on July 2, 2025.

To ensure confidentiality, all data were pseudonymized during transcription. Any names, locations or other personal details were replaced with pseudonyms.

The participants of the study received written study information and an informed consent document before the start of the study. Participants had the right to withdraw from the study at any stage without any consequence or without having to provide a reason, and their data would be excluded upon request.

4. Results

A total of ten GPs were recruited and interviewed. Their ages ranged from 27 to 55 years (mean age 36 years). Male-to-female ratio was 1:1. GPs from both rural and urban areas participated. Only one of the interviewed GPs had experience with pediatric palliative care: while on call, she was asked to perform a home-visit for a child with a neurological tumor who was in pain, despite palliative comfort therapy. The interviewee had no prior relation with the patient and during this single patient contact, she assisted in pain relief at home for the child. Since she was on call at the time, there was no opportunity for the interviewee to have further follow-up with the patient herself. She however did

mention that she felt like she was really able to help the patient during this home-visit, even though she felt a bit unsure of herself as she had only just started working as a GP at the time.
Nine themes were generated out of the interview data, which correspond to our research questions:

4.1 The perspectives of general practitioners regarding their role in pediatric palliative care

Although most of the interviewed GPs had limited or no firsthand experience with pediatric palliative care, they articulated a clear vision of how they could contribute, should they become more actively involved. In the data, five themes were identified that illuminate the nuances of their perceived roles.

a. GPs desire to be involved by default

Despite the fact that general practitioners are seldomly directly involved in pediatric palliative care, they expressed a strong desire to play a more substantial role in pediatric palliative care. This lack of experience was not interpreted as a lack of interest but rather as a structural absence of integration of general practice into the pediatric palliative care process. GPs recognized their peripheral position in the current model of care, which is predominantly specialist-driven, but seven out of ten believed this could - and should – change systematically, with the remaining three feeling that it should remain a personal choice whether or not to be involved as GP. All ten however did desire to be more involved themselves personally.

> *"I think it would be good if, as a general practitioner, you were involved in that kind of care by default. However, I think that in practice, that might not always be the case. It will likely depend on the extent to which you were already involved in the care during the palliative phase. From what I see, that is often not the case now, and primary care tends to be more in the hands of the pediatrician than the GP."* (GP 7)

> *"I do think we should have the ability to be involved* (in pediatric palliative care)*, and that as a GP you should be free to decide whether or not to take it on. (…) I think it should be a choice. But yes, definitely, I do think we certainly have a place in that palliative care"* (GP 10)

b. GP as an accessible and trusted provider of care:

A prominent theme across the interviews was the GPs envisioned role in delivering comfort-oriented care. All GPs emphasized their ability to provide basic symptom management—such as pain relief—

and psychological support for the child and their family. The accessibility of GPs, especially for home visits, was seen as an essential feature of their possible contribution.

> *"I imagine GPs would take a major role in symptom relief, in quickly responding to certain issues."* (GP 2)

In this context, GPs viewed themselves not as specialist doctors but as responsive, on-the-ground providers of holistic comfort care—available, approachable, and capable of offering timely interventions during distressing moments.

c. GP as a trusted figure for the family

Many GPs underscored the value of their pre-existing, long-term relationships with families. Their familiarity with the family dynamic, home environment and psychosocial background was seen as a major strength. This continuity of care enables them to identify latent needs that may go unnoticed in hospital settings.

> *"But I think that, as a general practitioner, you can play an important role because you might know the family, know the home situation, and perhaps identify needs that aren't visible in the hospital or that the specialist doesn't see."* (GP 7)

Such familiarity, participants believed, positions GPs as trusted confidants—not only for medical issues but for emotional and contextual support during the palliative process.

d. GPs as coordinators of care

The GPs often described themselves as potential intermediaries or coordinators within the complex web of pediatric palliative care. Given their comprehensive overview of a patient's general health and their links to various healthcare providers, GPs saw themselves as capable of bridging the gap between the family and the more fragmented world of specialist care. They envisioned a role that reduces redundancies, avoids unnecessary hospital visits, and ensures care is well-orchestrated at home.

> *"I would see myself also as a middleman between different healthcare providers, as someone who takes the responsibility that everything is well coordinated, especially when the patient is home."* (GP 10)

e. GPs as providers of generalist pediatric palliative care

While GPs expressed a willingness to be involved in pediatric palliative care, they also articulated the need for clear boundaries regarding the scope of their practice. They emphasized that certain highly

specialized treatments—such as chemotherapy, radiotherapy, and advanced psychotherapeutic support—fell outside their expertise. These responsibilities, they argued, should remain with pediatric specialists and multidisciplinary teams.

> *"I think certain treatments and more specialized symptom control — in the palliative context I'm thinking of radiotherapy, chemotherapy, certain surgical interventions for comfort — yes, those naturally fall under the responsibility of the specialist."* (GP 2)

> *"It's actually quite often about specific medical treatments for the underlying disease in oncology patients and so on. We don't have enough experience with that; that's not something we can do. My role would then be in symptom control — that is something we can do, possibly in consultation. (…) And that you can't provide specific psychotherapeutic support, as we're not really trained for that either."* (GP 6)

This nuanced delineation suggests a willingness to collaborate without overstepping professional boundaries, advocating instead for a complementary rather than substitutional role in pediatric palliative care.

4.2 Needs and barriers in providing pediatric palliative care

Regarding the potential challenges and support needs perceived by GPs regarding their involvement in pediatric palliative care, we identified three themes: (a) perception of insufficient knowledge, (b) emotional burden and (c) lack of structured communication and integration with specialist teams.

Although GPs expressed openness to provide pediatric palliative care, several internal and systemic factors shape the extent to which they can confidently engage in pediatric palliative care.

a. Insufficient knowledge of and competencies to provide pediatric palliative care

A recurring concern among participants was a perceived lack of knowledge and expertise related to pediatric palliative care, which they associated with a lack of training and clinical experience. GPs frequently reported feeling underprepared to manage the complexities of end-of-life care in children, particularly in relation to disease-specific knowledge, symptom management and psychosocial care. Despite this, some questioned whether comprehensive pediatric palliative care knowledge should be part of their core training or whether it is acceptable to acquire this knowledge on an as-needed basis, consistent with the broader generalist model of practice.

> *"I think I lack knowledge, especially regarding specific oncology related problems. (…) But I do think that if such a situation were to arise and I were called upon, I would*

commit myself to it and make sure to expand my knowledge and skills at that moment. (…) That's the case with everything in general practice, it's the idea of lifelong learning. Depending on the pathology that presents itself, or the patients who come to you, you continue to educate yourself in that area." (GP 7)

While acknowledging gaps in knowledge and limited experience in pediatric palliative care, GPs consistently expressed a willingness to expand their competencies and take on a more active role in pediatric palliative care.

b. Lack of structured communication and integration with specialist teams

GPs indicated that they are seldom involved when one of their pediatric patients transitions to palliative care and that they are often informed only at a later stage. They observed that, unlike in adult care where they are typically engaged early in the trajectory, their involvement in pediatric cases is limited. This lack of early inclusion contributed to a perceived sense of being sidelined from the care process.

"I'd personally like that (to be involved in pediatric palliative care*), because right now that doesn't happen in practice. It's something that happens only in hospitals. (…) It'd be nice to at least get a report from them."* (GP 3)

4.3 Wishes and suggestions in providing pediatric palliative

In line with the identified needs and perceived barriers, participants also articulated concrete wishes and suggestions for improving the conditions under which they could participate in pediatric palliative care. Their input focused primarily on two key areas: (a) improved communication and collaboration, and (b) structured support from specialized teams.

a. Need for improved communication and collaboration:

One of the most commonly cited challenges was the lack of communication between primary and secondary care providers. GPs reported that they are often left out of the information loop regarding the child's palliative trajectory, which hinders their ability to participate meaningfully. They highlighted the importance of clear and timely updates from hospital-based teams and pediatric specialists, preferably in the form of accessible written reports or direct communication.

"Here in our town, we get invited to multidisciplinary oncologic consultations of our (adult) patients. It would definitely be an added value if we could attend such consultations for children as well. I'd really like to. (…) If such situations arise, I'd

> *really appreciate it if the pediatrician would just give us a call. It's not something that is going to occur often, but that call would go a long way. These cases remain a sensitive matter."* (GP 1)

This lack of communication between healthcare providers creates both practical and psychological barriers for GPs to engage in pediatric palliative care, as GPs feel peripheral to the care process and unable to anticipate or prepare for involvement. Improved integration of primary care into the care trajectory of children with life-limiting conditions —ideally from the early stages—was seen as essential for enabling proactive engagement.

b. Desire for structured support from specialized teams:

In addition to improved communication, participants emphasized the importance of structured support from dedicated pediatric palliative care teams. Such teams, they suggested, could offer guidance, provide second opinions, and help navigate complex care decisions. Rather than replacing the GP's role, these teams would serve as a critical backbone that allows the GP to act confidently and effectively within their scope.

> *"I think Omega* (a local palliative support team for adults) *is amazing for adults — they're always available, incredibly knowledgeable, and super friendly. So if something like that existed for children, and I could easily call them without any barriers, that would be a huge help for me."* (GP 1)

This desire for structured support reflects an understanding of pediatric palliative care as inherently multidisciplinary, requiring coordination, expertise, and emotional resources that cannot be shouldered by GPs alone. Participants envisioned a collaborative model in which specialists and generalists work together, each contributing their unique strengths to the shared goal of comprehensive and compassionate care.

5. Discussion

5.1 Summary of main findings

This study explored the perspectives of GPs in Flanders, Belgium, on their role and involvement in pediatric palliative care. Although only one participant had direct prior experience with a pediatric palliative care case, most expressed a strong willingness to be involved. Their limited engagement was attributed less to unwillingness and more to structural factors, particularly the absence of formal inclusion in care trajectories that are typically initiated and managed in hospitals. These findings

resonate with earlier studies in the UK and Canada, where GPs similarly reported feeling sidelined once a child entered specialist care (22,23,28). This feeling may be reinforced by the fact that, in Belgium, pediatricians often provide an important part of the primary care for children instead of GPs, even though their consultations should ideally be reserved for specialist care. This misalignment in who delivers primary care makes it even easier for some young patients to disappear into specialist care.

Participants emphasized the unique strengths they can bring to pediatric palliative care: trusted and ongoing relationships with families, the ability to provide continuity of care at home and a holistic, generalist approach that addresses both medical and psychosocial needs. These insights underscore how generalist care could be more effectively integrated into pediatric palliative pathways in a healthcare system where hospital-based specialists currently play the dominant role.

5.2 Strengths and weaknesses of the study

A key strength of this study is that it captures the voices of GPs across diverse practice settings in Flanders. The inclusion of participants from both rural and urban areas enhances the relevance of findings for the broader Flemish GP population. The semi-structured interview design allowed participants to speak freely while ensuring comparability across interviews and thematic analysis enabled systematic identification of themes.

However, the study also has limitations. The small, self-selected sample may reflect GPs who were already more motivated or interested in pediatric palliative care, which could lead to an overrepresentation of positive attitudes. In addition, the focus was on self-reported perspectives rather than actual observed behavior, which may not fully capture the realities of pediatric palliative care engagement in practice. For practical reasons, the analysis and interpretations of the interviews was done by the main researcher only, who is a GP himself. This insider position had clear benefits: it provided a deep understanding of the clinical and organizational context, helped build trust and rapport with participants, and made it easier to recognize subtle cues in language, priorities, and work culture that an outsider might have overlooked. However, it also carried some risks. Sharing the same professional background as participants may have led to unspoken assumptions, less probing of certain topics, or interpretations shaped, consciously or unconsciously, by the researcher's own experiences and beliefs about the GP role in palliative care. To reduce these risks, the researcher used reflexive strategies such as keeping analytic notes, reviewing coding decisions, and discussing emerging ideas with a supervisor. Even so, the lack of a second independent coder meant there were fewer opportunities to challenge interpretations from a different perspective. Finally, the absence of parent or specialist perspectives limits the comprehensiveness of the findings. Future research

should triangulate these perspectives and evaluate pilot models of structured GP–specialist collaboration in pediatric palliative care.

5.3 Discussion of research question 1: GP perspectives on their role in pediatric palliative care

GPs in this study described themselves as willing but underutilized contributors to pediatric palliative care. Their reflections highlight the complementary role they envision, focused on providing comfort care, psychosocial support, and continuity within the home environment. Importantly, participants did not seek to replace pediatric specialists but emphasized their potential as accessible, trusted caregivers who can maintain communication and coordination across care providers. These findings align with evidence from adult palliative care, where GP involvement has been associated with improved symptom management, better care coordination, and enhanced patient and caregiver satisfaction (8–10,12,13).

This understanding reflects the generalist–specialist divide in palliative care: GPs are prepared to provide foundational care while relying on specialized teams for more complex interventions (38,39). Their potential role as care coordinators aligns with the formal aims of Belgium's Pediatric Liaison Teams, which are designed to, inter alia, ensure continuity of care (34). However, participants noted that this integration remains inconsistent in practice, highlighting an underused strength of general practice in the Belgian pediatric palliative care context. One practical way to ensure better integration of general practitioners in pediatric palliative care is to establish a formalized, structured handover process. For example, when a child enters the palliative phase, the specialist or liaison team could be required to initiate a direct phone call or video consultation with the GP. This initial contact could then serve to introduce the care plan, clarify the GP's role, and address any immediate questions.

5.4 Discussion of research question 2: Possible barriers and support needs in providing pediatric palliative care

The most prominent barrier identified was insufficient pediatric palliative care-specific knowledge. Participants reported limited confidence in managing pediatric symptoms, dosing medications, or navigating the emotional complexities unique to pediatric palliative care. Nonetheless, most viewed these as surmountable challenges rather than fixed limitations. They emphasized their openness to case-based learning and continuous professional development, supporting prior research that suggests GPs may not need comprehensive pediatric palliative care training but do benefit from timely, case-specific guidance (22,23). This feeling highlights a tension: while pediatric palliative care cases are rare, they carry high stakes, which can clash with the GPs generalist role. Since these cases

don't come up often, learning on a case-by-case basis seems practical, but it can also lead to inconsistent care and uneven preparedness.

While acknowledging the emotional weight of pediatric palliative care, participants did not see this as a reason to withdraw. Instead, they accepted emotional challenges as an intrinsic aspect of their caregiving role, comparable to experiences in adult palliative care. This finding challenges the common assumption that pediatric palliative care may be “too emotionally difficult” for GPs, instead portraying them as resilient and willing participants when adequate support is in place.

Another systemic barrier was the lack of structured communication and integration with hospital-based teams. GPs frequently reported learning of a child’s palliative status late or not at all, limiting their ability to participate proactively. This led to feelings of exclusion and professional disconnect. While palliative liaison teams are formally tasked with involving GPs, participants felt this was not consistently achieved in practice (34).

5.5 Discussion of research question 3: Barriers and opportunities for enhancing the engagement of GPs

Participants identified clear opportunities to strengthen their involvement in pediatric palliative care. First, they emphasized the need for better communication with pediatric specialists. Simple actions such as a phone call, a written update or an invitation to a multidisciplinary meeting were described as highly meaningful for fostering inclusion.

Second, GPs called for easily accessible support from specialized pediatric palliative care teams. They envisioned a pediatric equivalent to the well-established adult palliative consult teams, which are readily available to provide reassurance, advice, and backup. Such structured support would enable GPs to contribute confidently within their scope, knowing that expert guidance is available when needed. Notably, all participants that advocated for said support teams were unaware of whether such services already existed in Belgium, reflecting the disconnect between GPs and the aforementioned palliative liaison teams (the support teams in question).

5.6 Implications for education, practice, policy, and research

As the demand for palliative care grows and care increasingly shifts from hospitals to home settings, integrating GPs more fully into pediatric palliative care networks will become even more important (2,4,40). This trend underlines the urgency of addressing the barriers identified in this study and ensuring that GPs are equipped and supported to fulfill their potential role. Additionally, the professional environment within which the GP operates needs to adapt so that the opportunity arises for GPs to become active participants in the care for a child with palliative care needs.

a. Education

The results indicate that GPs would benefit from targeted training in pediatric palliative care, particularly around symptom management, communication with families, and care coordination. Until recently, palliative care was not taught in the curriculum of Medicine in Belgium and thus only the most recent generation of Belgian physicians has received some level of theoretical education on the topic. At this moment, courses on palliative care are part of the regular curriculum of Medicine in Belgium. However, these rarely, if ever, touch on the subject of pediatric palliative medicine. This applies to the postgraduate curriculum of General Medicine as well.

Brief, case-based modules integrated into postgraduate training could help address the aforementioned needs. Such initiatives are in line with broader recommendations as those from the European Association for Palliative Care (EAPC) that highlight competencies in communication, teamwork and self-awareness as essential elements of palliative care education (41). While GPs do not necessarily need comprehensive specialist training for pediatric palliative care, access to practical, case-relevant guidance could enhance their confidence and preparedness.

b. Practice

Mechanisms should be established to ensure that GPs are systematically included in pediatric palliative care trajectories. Simple measures, such as timely phone calls, written updates or invitations to multidisciplinary meetings, can foster early and meaningful involvement. Strengthening collaboration with pediatric liaison teams would also help GPs provide continuity of care while maintaining close connections with families. For this to take place, GPs need to be recognized for their expertise in the patient's medical history and social background.

c. Policy

Policymakers should ensure that palliative liaison teams routinely involve GPs in pediatric palliative care trajectories and make their consultative role more visible and accessible. Funding and organizational frameworks could support the creation of easily reachable pediatric consult teams modeled after adult services.

d. Research

Future research should explore how targeted training and structured collaboration models affect GP engagement in pediatric palliative care. In addition, studies incorporating the perspectives of

parents and pediatric specialists could provide a more comprehensive understanding of how best to integrate GPs into palliative trajectories for children.

6. Conclusion

While these findings are based on a small sample, they point to the possibility that practitioners in Flanders may be motivated and willing to play a more active role in pediatric palliative care but remain underutilized due to structural exclusion, insufficient communication and limited pediatric palliative care-specific training. Their trusted relationships, accessibility, and holistic approach position them uniquely to support children and families facing life-limiting conditions. Addressing knowledge gaps, strengthening structural communication and providing accessible specialist support are crucial steps toward realizing their potential contribution.

7. Annex 1: Interview topic guide

- How would you describe pediatric palliative care?
- What do you see as the key goals and principles of pediatric palliative care?
- Do you think that GPs should be involved in pediatric palliative care?
    - If so, in what capacity?
    - If no, why do you believe this should not be so?
    - Are there specific aspects of pediatric palliative care that you feel that fall outside of your expertise?
- Have you come into contact with pediatric palliative care in practice?
    - If so:
        - Can you describe a specific case or situation?
        - What went well in those instances?
        - What challenges did you face, what could be improved?
        - What other professionals were involved in this process?
        - How do you evaluate their cooperation?
        - Were there clear roles and responsibilities among different professionals?
        - Were you satisfied with your role in this process?
        - Did you feel comfortable and confident in their role during the pediatric palliative care process?
        - Were there any specific aspects of care where you felt particularly useful?
        - Were there moments where you felt unsure, unsupported, or out of your depth?
        - How did you emotionally process his involvement in pediatric palliative care cases?
- Do you feel like you have the necessary knowledge/skills to provide pediatric palliative care?
    - If so, did you follow any additional courses or training on the subject?
    - If no:
        - What specific knowledge or skills do you feel you lack?
        - Do you feel like you have access to the necessary resources to deepen your knowledge/better your skills on the subject?
- Are there barriers which withhold you from practicing pediatric palliative care?

    - If yes, what are these barriers?
    - What could have helped to make you feel more supported in your role?
- In your opinion, what aspects could be enhanced to facilitate the delivery of pediatric palliative care (if you show an interest in being involved in pediatric palliative care)?
- Would you like to add anything spontaneously to the interview?

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