| Table S1 Relevant information extracted from the selected studies | | | | | | | |
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| Authors De Clercq et al. (10) | Country/region Switzerland | Local Pediatric Oncology Group Centers | HCPs Doctors, psychologists, nurses, and social workers | Patients Pediatric oncology patients | Data collection Focus group interviews | Findings Most participants associated pediatric PC with non-curative treatment. They reported difficulties in addressing PC services to families due to the strong stigma surrounding this term. They also thought that the notion of PC is very much linked to a policy context, and difficult to reconcile with children's | Highlights Positive word-of-mouth by satisfied families and healthcare providers might be a more sustainable way to advocate for pediatric PC than replacing it with a euphemistic term |
| Fairlamb and Murtagh (11) | UK | PC Research Center | Doctors | People with end-stage heart or respiratory diseases | In-depth interviews | everyday life Better integration of advance care planning discussions earlier in the disease trajectory is needed to enable timely referral to PC. A cultural shift needs to be made regarding public awareness of end-stage cardiac and respiratory diseases and | Increased interdepartmental working for HCPs via joint educational and clinical meetings is perceived as likely to support earlier and increased referral to specialist PC services |
| Low <i>et al.</i> (12) | UK | Not specified (online search) | Doctors | Cirrhosis of the liver | On-line questionnaire survey | the value of PC Identify symptom management, prognostication, and overall service structure as key areas for future research | It was the first UK national survey to specifically explore current attitudes and practices of different HCPs caring for patients with cirrhosis near the end of life, using on-line |
| Mitchell et al. (13) | England | Hospital | Doctors, nurses, HCPs | Not specified | Focus groups | There is a need to understand how to integrate PC much more effectively into the care of children and young people who could benefit from it | survey methodology Specialist pediatric PC services have an important role in legitimizing and remodeling the PC approach within healthcare organizations |
| Silva et al. (14) | Portugal | Hospital | Doctors, nurses | Neonatal patients | Semi-structured interview | It was evident that HCPs have a hard time talking about their personal experience in providing care to newborns facing an end-of-life situation and to their family | It was evident that HCPs have a hard time talking about their personal experience in providing care to newborns facing an end-of-life situation and to their family. Evidence provided by their answers unveils their humanity as they share the feelings they have experienced: pain, sadness, suffering, frustration, but also the respect and the empathy they feel when they provide care for the NB and for his family. HCPs experience difficulties in making end-of life decisions and claimed they had already experienced conflict situations due to differences of opinions and because of the inexistence of protocols that would surely have helped them deal with those situations |
| Siouta et al. (15) | Belgium | Hospital | Doctors | Cardiology and pulmonology patients | Interviews in person or via phone | Misconceptions about PC and its association to death/end-of- life seem to be significant reasons for the limited participation of PC specialists and the late initiation of PC itself | Targeted education and improved communication could raise awareness of PC aspects among all parties involved |
| Wallerstedt et al. (7) | Sweden | Nursing, retirement homes, and home care | Doctors, nurses, paramedics, managers | Not specified | Focus group interviews | The results revealed three domains: a blurred conceptual understanding, a challenge communicating transitions and a need for interprofessional collaboration. There is also an urgent need for education and training in PC for HCPs | Further research is needed regarding whether a more integrated understanding of the concept PC may improve the quality of PC |
| Winger et al. (16) | Norway | Pediatric units in hospitals | Doctors, nurses, social workers psychologists, physiotherapists | Children with life-threatening conditions | Focus groups | HCPs highlighted quality of life, total care for the child and the child's family and interdisciplinary collaboration as core elements | Attention to and knowledge among HCPs might change the perception about PC from a frightening concept to one that is accepted by all parties, implemented in practice, and used as intended |
| Wright and Forbes (17) | England | Tertiary bone marrow reference centers | Doctors | Patients dying of hematological malignancy | In-depth face-to-face interviews | While positive attitudes towards PC were expressed, barriers to collaboration between hematology and specialist PC services were identified and provided opportunities for improved interdisciplinary working | Suggestions for improvement are focused around: improved training; enhanced mutual respect and understanding; clearer definition of the role of specialist PC services; and consistency and flexibility in service provision |
| Ziehm et al. (18) | Germany | Not specified | Doctors, nurses | Chronic heart failure | Online-survey | A lack of knowledge about the content and measures of PC, poor communication and unclear responsibilities between medical disciplines, difficulties to determine the right time to initiate PC, and the feeling not to be prepared to discuss end-of-life issues with the patient has been identified as barriers | Information and education encompassing the aim, content and measures of PC needs to be provided for all parties in order to optimize patient care, to foster communication between HCPs, patients, and relatives, and to overcome perceived barriers |
| Bar <i>et al.</i> (19) | USA | Neurological ICU | Doctors, nurses, and fellows | Patients in the neurological ICU | Online survey questionnaire | A better understanding of the PC needs specific to patients and families in the neuro-ICU as well as the effect of PC consultations on long-term outcome may assist in the timely and appropriate use of PC specialists | Provides insights into the current perceptions, practice patterns, and preferences of neurointensivists as it relates to PC consultation in the neuro-ICU |
| Cheung et al. (20) | USA | School hospital | Doctors, nurses, social workers, and case managers | Patients with chronic diseases and end-of-life care | Surveys/questionnaires | Perception of palliative medicine concepts by health care professionals was learned at a teaching community hospital in two studies separated by 14 years. The results of the two studies were essentially similar; attendance of educational | Active interaction with PC teams is key to the development of such "palliative attitude". A "palliative attitude" of health care professionals is essential for the promotion of palliative medicine |
| Kyc <i>et al.</i> (21) | USA | ICU neonatal | Doctors, nurses | Neonatal ICU patients | NiPCAS survey | activities and confidence in PC were higher 14 years later Six facilitators to neonatal PC were identified: (I) support of PC by the health care team; (II) support of PC by medical and nursing practice; (III) agreement that PC is as important as curative care; (IV) parental involvement in decision making; (V) recognition of the importance of PC education; and (VI) prioritizing pain relief. Three barriers to neonatal PC were highlighted: (I) a physical environment that is not conducive to providing PC; (II) technological obligations and parental demands; and (III) the societal belief that babies should not die | Several facilitators and barriers of neonatal PC were identified. There were similarities and differences in perceptions of neonatal PC between medical and nursing staff |
| LeBlanc et al. (22) | USA | Academic cancer centers | Doctors | Cancer | In-depth interviews | Most hematologic oncologists view PC as end-of-life care, whereas solid tumor oncologists more often view PC as a subspecialty for comanaging patients with complex cases. Efforts to integrate PC into hematologic malignancy practices will require solutions that address unique barriers to PC referral experienced by hematologic malignancy specialists | Striking differences in referral practices, perceptions, and attitudes regarding PC between hematologic oncologists and solid tumor oncologists |
| McNeil et al. (23) | Latin America | Hospital | Doctors | Childhood cancer | ADAPT survey | Regionally adapted educational interventions appear to be needed to improve physicians' abilities to address patients' physical, emotional, and spiritual needs along with grief and bereavement care for families | Beyond informing educational efforts, results from this study will be used to advise local leaders in Latin America on educational priorities to improve PC for children with cancer |
| Neiman (24) | USA | Hospital | Nurses | Hmong patients in general | Semi structured interview | Three major themes were identified in the data; assisting tradition, understanding culture, and managing language barrier. Nurses experienced uncertainty and inadequacy of resources when caring for patients from a Hmong background. Nurses also recognized the strong family ties in this specific population and the importance of supporting tradition while in the hospital | Utilizing Wood and Schwass' framework of cultural safety could guide nurses providing basic PC to Hmong patients and other culturally diverse patients |
| Ufere et al. (25) | USA | Hospitals and clinics | Doctors | End-stage liver disease | Survey | Most physicians believed that centers providing care to patients with end-stage liver disease should have PC services. Only a minority reported collaborating frequently with inpatient or outpatient PC services. Most believed that when patients hear the term PC, they feel scared and anxious. Most believed that patients would think nothing more could be done for their underlying disease if a PC referral was suggested | Specific interventions are needed to overcome misperceptions in equating PC with end-of-life care and to enhance collaboration with PC services for patients with end-stage liver disease |
| Silva et al. (26) | Brazil | School hospital | Doctors, nurses, nursing technicians, psychologists, social workers, physical educators, pedagogues, nutritionists, pharmacists | Childhood cancer | Semi-structured interview | The following four themes emerged from analysis: PC: conceptions of the multi-professional team; the construction of singular care; the facilitations and difficulties experienced by the team and significant lessons learned | The subjects revealed that the team also suffers with the death of a child and, like the family, moves toward the construction of coping mechanisms for the elaboration of mourning. Paradoxically, the team shares knowledge to determine the foundations of a singular therapeutic project and inserts the family in this process so that it can be the protagonist of the child's care |
| da Silva <i>et al.</i> (27) | Brazil | ICU | Doctors, nurses, physiotherapists, nutritionists | ICU patients | Semi structured interview | Three thematic categories: assisting the terminally ill patient in the ICU by promoting physical comfort; unpreparedness of the multiprofessional team in dealing with the terminally ill critical patient; and challenges in practicing PC in the intensive care | It is necessary to draw up a national policy that supports care for the terminally ill, as well as continuing education for professionals and the creation of care protocols to promote comfort for the patient and their family during the |
| Gulini et al. (28) | Brazil | ICU | Doctors, nurses, nursing technicians, physiotherapists | ICU patients | Semi structured interview | environment The key ideas extracted from the interviews were: care in the end stage of life that avoids futile measures; comfort care; lack of standardized care and lack of team training | final phase of life The professionals perceived PC as appropriate in the last stages of life, with no need for futile treatment or as comfort measures. However, they are aware of the lack of standardization and lack of capacity building in this area, which leads them to conceive PC as terminal care, and |
| Boaventura et al. (29) | Brazil | Pre-hospital care service | Doctors, nurses, nursing technicians, and first aiders | Emergency medical patients | Interview | Three central themes emerged out of the professionals' speeches: (I) unpreparedness of the team; (II) decision making; and (III) dysthanasia | It is necessary to invest in professional training associated with PC in the home context and its principles, such as: affirming life and considering death as a normal process not rushing or postponing death; integrating the psychological and spiritual aspects of patient and family care, including grief counseling and improved quality of life, adopting a specific policy for PC that involves all levels of care, including pre-hospital care, and adopt a unified information system, as well as more effective procedures that favor the respect for the patients' will, without generating dissatisfaction to the team and the family |
| Baliza et al. (30) | Brazil | Hospital | Nurses | ICU | Semi-structured interviews | The inductive thematic analysis enabled us to identify four themes: the cultural context of the ICU: decision-making <i>in situ</i> ations of end-of-life; beliefs and subjectivity of care in end-of life situations; professional experience and context characteristics of end-of-life care situations; and humanization practices in end-of-life situations: the patient and family centered care | Professional maturity, the ability to transmit information and the ability to negotiate are directly related to the inclusion of nurses in the decision-making process |
| Ehrlich et al. (31) | Eurasia | Pediatric Oncology Group | Doctors | Childhood cancer | ADAPT survey | responses from 11 countries in Eurasia | This work reveals wide variability in alignment of provider knowledge with WHO guidelines and limited confidence in providing PC to children with cancer |
| Hahne <i>et al.</i> (32) | China | Tertiary hospital | Doctors | Hematology or oncology patients | Semi-structured interviews | Most physicians viewed PC as equivalent to end-of-life care, while a minority considered it possible to integrate PC with active treatment. Physicians described experiencing ethical tension between the desire of family members to protect the patient from knowing they have advanced cancer, and the | As PC access expands in China, medical training should encourage earlier integration of PC for advanced cancer, address ethical issues faced by physicians communicating about PC, and establish guidance on the role of the physician in discussions about goals of care |
| Tay et al. (33) | Singapore | Hospital | Doctors, nurses | Chronic non-malignant diseases | Online questionnaire | patient's "right to decide" about palliative treatment Gaps in understanding and the ability of nurses and physicians to communicate end of life issues, introduce PC services to patients and their families and confront sociocultural issues suggest the need for a longitudinal training program. With similar concerns likely prevalent in other clinical settings within this island nation, a concerted national education program targeting obstacles surrounding effective PC should be considered | continuing this discussion |
| Ugur <i>et al.</i> (34) | Turkey | Hospital | Nurses | Cancer Childhood cancer | Questionnaire | The most important obstacles were insufficient education, communication, and health policies | In-service PC training should be planned for nurses at regular intervals and health policy should be organized |
| Yu et al. (35) Monterosso et al. (36) | South Korea Australia | Tertiary hospital Hospital | Doctors Doctors, nurses, HCPs | Childhood cancer Not specified | Questionnaire Focus groups and surveys | Lack of workforce and facilities specialized in PC and patients' or caregivers' negative recognition were reported as the main barriers to PC implementation Key themes identified from the four focus groups were (I) | To promote PC provision and improve the quality of life of pediatric patients and their families, it is important to introduce PC early into disease-modifying treatment at any level of health care Results confirmed that innovative approaches to education |
| | Associate " | | Destru | | | delays or nonreferral to PC created considerable stress and feelings of inadequacy despite a perceived understanding of the broader definition of PC; and (II) HCPs commonly focused on end-of-life care | and upskilling HCPs in PC and referral pathways is warranted |
| Russ et al. (37) | Australia | Emergency department | Doctors, nurses | Emergency room patients | Questionnaire | Suggests that although respondents support the initiation and provision of PC in the emergency department, more education around which patients would benefit from this approach is needed Most respondents reported 'limited' or 'working' knowledge of | Areas suggested for further education include communication and ethical issues surrounding end-of-life care |
| Shearer et al. (38) | Australia | Emergency department | Doctors, nurses | Emergency room patients | Surveys/questionnaires | Most respondents reported 'limited' or 'working' knowledge of PC only. A greater proportion of nursing staff reported having 'limited knowledge' compared with medical staff, but the proportion of staff who held graduate or higher qualifications in PC were the same for both groups | Emergency room staff express confidence regarding symptom management in PC; potentially underestimate the role of a palliative approach in non-cancer diagnoses and seek additional education in areas such as end-of-life communication and ethical issues |
| Weil <i>et al.</i> (39) | Australia | Emergency department | HCPs | Cancer | Focus groups and semi- structured interviews | The overarching theme was that HCPs held contradictory understandings of PC and its application in the emergency department | There are entrenched contradictions and tensions surrounding the term "PC"; confronting these is likely to require more than re-branding, and will promote better care for this vulnerable patient group in the emergency department |
| Balkin et al. (40) | Around the world | Hospitals and clinics | Doctors | Children with neuroblastoma | Online survey questionnaire | Most respondents trained in high-income countries but practice in low- and middle-income countries, and care for more than five patients with neuroblastoma annually | Increased perceived competence was associated with training, which supports the need for increased PC education |