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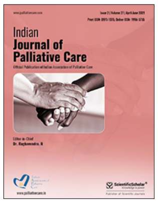

Review Article

Parental Perspective in Paediatric Palliative Care: A Systematic Review of Literature Using the PRISMA Method

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ABSTRACT

Research in Parental Perspectives are pivotal in gaining understanding of parents' experiences, issues, concerns and attitude in pediatric palliative care which affects their decision making. However only a limited number of such studies have included the first-person perspective of Parents. The aim of this article is to understand the contribution of previous research on parental perspectives in pediatric palliative care through a systematic review of literature. Nine articles that met the inclusion criteria were accessed and seven key themes emerged; Psychological perspective, parental concerns, parental needs, parental attitude, spiritual perspective, cultural perspective and financial perspective. This review highlights requirement of more research into parental perspective if possible, covering all key aspects along with additional research in cultural perspective and development of validated tools, checklists and psychometric questionnaires for the assessment of these perspectives in various domains: spiritual, financial, psychological, cultural and social.

Keywords: Paediatric palliative care, Parental concerns, Perspective, Communication, Decision-making

INTRODUCTION

Palliative care is a relatively new concept in India with its history dating back to only the mid-1980s,[1] with only 1% of the population having access to it[2] and this 1% constitutes the total population including children. Given the current situation, it is evident that access to paediatric palliative care facilities for children is limited and faces a lack of corpus funds.[3] The concept of paediatric palliative care in India would require a major cultural adaptation[4] considering parent's reservations about western medications where they may often opt for complimentary medicines and avoid important decisions regarding lifesaving surgeries fearing it would lead to disfigurement harming future prospects of marriage.[4] This also suggests that the awareness among the general population regarding the paediatric palliative care is limited. In such situations when the question of making important decisions for the well-being of their children arises, caregivers may face a tremendous amount of stress which, in turn, creates barriers in decision-making and denial in caregivers.[5] This may hinder important decision-making, for example, even after knowing there is no curative treatment available, the caregivers may still want to aggressively continue treatment instead of focusing more on comfort care or palliative care. Not only the socio-cultural but also psychological and socioeconomic factors contribute as a major barrier in end-of-life care and decision making.[6] Several barriers to communication such as paternalism in medicine, inadequate training in communication skills, knowledge of the grieving process, special issues related to caring of children and cultural barriers were noticed in paediatric palliative care,[4] among which need and lack of proper communication for caregivers has been an emerging key theme in Indian paediatric palliative care services that impact major treatment related decisions that require to be taken both by the caregivers and care team.[7,8] To fill these communication gaps a necessity of counselling guidelines seems evident.[4] What could also help is a communication tool to the likeliness of the Serious Illness Conversation Guide (SICG) program developed by Ariadne Labs[9] Bernacki *et al*., 2014, 2019). The SICG, developed by Ariadne Labs, a Joint Centre for Health Systems Innovation (Boston, MA, USA), is a structured communication tool that provides clinicians with psychologically informed language to assess

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illness understanding and patient information preferences; share prognosis according to patient preferences; explore patient values, goals and care preferences; and make recommendations based on patient priorities.[9,10] There is also a paediatric adaptation of the guide by the name of SICG-peds to use it for communication with caregivers of children.[11,12] There are other tools available as well that could assist in communication and shared decision making.[13] However, considering how diverse the Indian population is and how cultural factors affect decision-making and communication these tools may require major modifications to be made fit for use for the Indian population. The development of a culturally appropriate communication quality improvement tool would require inputs from both clinicians and caregivers.

Caring for a child who requires palliative care services, or is diagnosed with a life-limiting illness is not easy. Several studies suggest that parents of a child with a life-limiting illness are often exhausted, suffer from emotional and physical distress, and report below-average quality of life.[14,15] These concerns, issues, and needs may require special attention before any counselling guideline or communication tool could be put to work, in fact, these tools should be made so keeping in mind the perspectives of parents.

Hence, it is hypothesized that to create a communication tool or a counselling guideline, understanding of the parent's perspective is much required. Therefore, we contend that a comprehensive analysis through a systematic review of available literature on parental perspectives in the context of paediatric palliative care in India would contribute to having a better understanding of the needs and concerns of Indian parents, consequently contributing towards the development of better, culturally-fitted communication and counselling guidelines. It would also help us gain insight into the literature gaps concerning parental perspectives in paediatric palliative care and future research needs.

MATERIALS AND METHODS

The study implemented a systematic literature review in line with the reporting checklist of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses.[16] For this study, a comprehensive literature search was undertaken to identify literature centring on parental perspectives, attitudes, concerns, and needs in paediatric palliative care in oncology. The main aim was to review original data regarding caregiver's perspective (what parents value?), their attitude (involving their children in knowing diagnosis and prognosis along with attitude toward shared decision making), their needs (treatment support, communication needs, emotional needs, socio-economic needs and expectations from the care team and finally, their concerns (Emotional distress, child's comfort and end-of-life care decision-making.) To narrow the search criteria down, PPC papers published only in an oncology setting were selected.

Search strategy

The following databases were searched in August 2020: PubMed (Jan 2010-Jan 2020) and the Indian Journal of Palliative Care (IJPC) (2010–2020). Reference lists from retrieved and selected articles were hand-searched.

Search terms

PubMed

Search: (Paediatric OR Paediatric OR Child*) AND Palliative AND (Caregivers OR Parent*) AND (Communication OR decision OR spirituality OR burden OR Psycho* OR emotion* OR expectation OR Concern OR Attitude) AND (India[Affiliation]) Filters: from 2010/1/1 - 2020/1/1.

IJPC

'[WORD] - paediatric palliative care, cancer, parental concerns, perspective, communication,' from 2010 to 2020 (First searched on August 2020, last accessed on June 2021 for rechecking purposes).

Inclusion and exclusion criteria

A protocol was developed in advance to document the analysis method and inclusion criteria. We utilized PubMed and IJPC to search for papers published on studies done on the perspective of Indian caregivers keeping in mind the socio-cultural factors that effects opinion and decision-making attitude,[7] irrespective of the setting.

Inclusion criteria

- Articles published in English
- Data involving perspective, attitude, needs, and concerns of Indian caregivers of paediatric palliative care patients with cancer
- Data of Indian Caregivers/parents
- Papers published within the years 2010–2020.

Exclusion criteria

- Case studies, commentaries, editorials, and case reviews
- Non-oncology paediatric palliative care papers
- Studies were done on the non-Indian population
- Grey literature.

Data extraction and analysis

The title, abstract, keywords, authors' names and affiliations, journal name, and year of publication of the identified records were exported to Zotero for review. Two independent reviewers screened the titles and abstracts of the records independently and papers were selected and discarded in line with inclusion and exclusion criteria. The bibliographic details of the extracted data were sorted and arranged in Zotero for data management and the data were sorted and selected against the essential items of PRISMA checklist, please refer to the [Appendix A]. Then, the two reviewers performed an eligibility assessment by carefully screening the full texts of the remaining papers independently. During this phase, disagreements between the reviewers were discussed and resolved by consensus. If no agreement could be reached, the views of a third reviewer would have been taken into consideration.

Subsequently, all the included papers were carefully reviewed to extract and code the data.

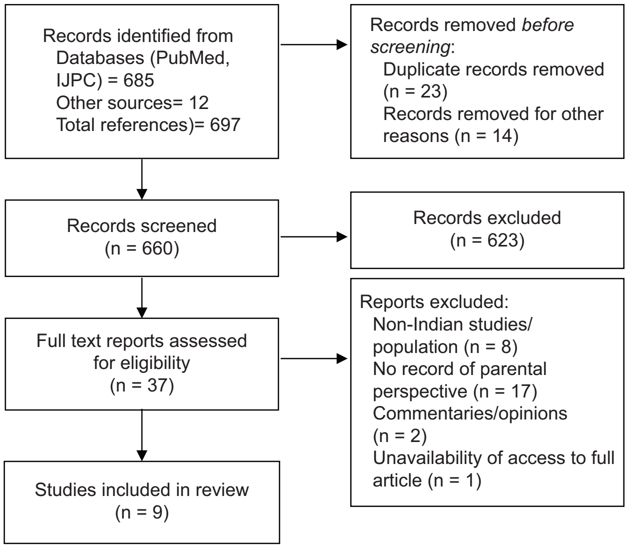
RESULTS

Number of identified literature after database search turned out to be 685 combined results of PubMed and IJPC. 12 papers were selected from the citations of the records identified in the data base search, out of a total of 697 titles 37 papers were selected for full text analysis. Finally, a total of nine studies were selected for review that met the inclusion list criteria. The study selection process using the PRISMA checklist is summarized in [Table 1].

Summary of literature

Of the nine studies, one was a review of paediatric palliative care in India,[17] two studies were specifically conducted on mother's perspectives,[18] one study was an in-group correlational design that analysed Coping, spirituality, and Caregiver's burden between father and mother,[19] while one study drew a comparative analysis between caregivers of survivors versus non-survivors in respect to their psychosocial, spiritual and financial concerns.[20] However, two independently published studies submitted 5 years apart overlapped significantly in focus, content, and data with slight variations in data findings,[4,8] but since one specifically focused on the cultural perspective of communication[4] while the other on parental attitude and communication,[8] both the studies were included in the study.

Table 1: PRISMA flowchart of search results.



Data findings are reported in [Table 2].

Key themes

After reviewing the studies for parental perspectives of paediatric patients undergoing cancer treatment, several key themes were identified from the text which emerged frequently. The key dimensions in parental perspectives are noted below.

Psychological perspective

Psychological perspectives included but not limited to were;

- Caregiver's Burden
- Emotional experiences; both of child and parent and how these experiences affected each other
- Coping strategies
- Emotional distress
- Substance abuse.

Attitude

Major parental attitudes discussed in the studies were;

- Parental attitude toward disclosing diagnosis, prognosis, and treatment-related information with the child
- Parental attitude toward shared decision-making.

Needs

Key needs identified were;

- Parental needs for emotional support
- Communication needs; what parents want and value?
- Expectations from care team/treating doctor
- Spiritual needs
- Socio-economic needs.
- Information about the child's diagnosis, prognosis, and treatment.

Concerns

Parental concerns noticed but not limited to were;

- Parental concerns for the quality of life
- Symptom management
- Characteristics of death
- End of life decision-making
- Treatment and treatment outcomes
- Financial concerns.

Cultural perspective

Important cultural perspectives identified were;

- Cultural perspective affecting decision making
- Thinking patterns.

Financial perspective

- Financial burden
- Insurance
- Borrowing money or selling assets

Table 2: Summary of studies selected for review (Table continued from Page 24 till 28).

Author and Year, Country Affiliation	**Title**	**Aim**	**Sample size and Method**	**Findings**	**Conclusion**
Author: Usha Chivukula, Sirisha Kota and Durgesh Nandinee Year: 2018; Country: India	Burden Experience of Caregivers of Acute Lymphoblastic Leukaemia: Impact of Coping and Spirituality	To investigate the impact of coping and spirituality on caregiver burden	100 caregivers of children between the age group of 3–11 years, diagnosed with acute lymphoblastic leukaemia. Multiple linear regression analysis along with correlational design between Coping, spirituality and Caregiver's burden. Used instruments, The brief cope, Spirituality Scale and The Caregiver burden inventory	(1) Both caregivers experience similar levels of caregiver burden regardless of Gender. (2) Mothers use coping techniques such as emotional support, use of instrumental support and religion. (3) Fathers were found to use substance use and acceptance as coping strategies	(1) Need for professional help in handling Caregiver's physical and emotional distress. (2) Need for planning and designing effective interventions. (3) Need a professional health psychologist could be a liaison between the doctor, patient and the caregiver in bringing down the levels of burden and psychological distress in caregivers as well as patients
Author: Gem Mohan, Julius X Scott, Rizwana Nasrin, Latha Sneha, Rakesh Manohar, Lalitha Subramanian, Sowmiya Narayani, Aruna Rajendran Year: 2016 Country: India	First Counselling Revealing the Diagnosis of Childhood Cancer: Parent Preferences From an Indian Perspective	To find out the preferences among parents of Indian children with cancer regarding communication and breaking of bad news when fully informed about the diagnosis	A sample of 60 parents who had been counselled within 3 months from diagnosis. A qualitative method, structured interview with a questionnaire	(1) All parents agreed on the importance of first counselling. (2) 83% of parents wanted a comparison with another child having the same diagnosis. (3) 57% wanted the immediate or extended family to be present. (4) 92% did not want support staff to be present during counselling. (5) 68% of parents did not want to reveal the diagnosis to the child. (6) 77% wanted as much information about the disease as possible, including the estimated cost of treatment. (7) 90% wanted access to other information services and information about other centres where treatment was available	Parents have preferences about how information is presented to them during the first counselling. Knowing these preferences will help physicians to better their ability to interact with parents in the future during first counselling and help them decide a culturally appropriate course of action

(Contd...)

Table 2: *(Continued)*

Author and Year, Country Affiliation	Title	Aim	Sample size and Method	Findings	Conclusion
Author: Maryann Muckaden, Manjiri Dighe, PD Balaji, Sunil Dhiliwal, Prajakta Tilve, Sunita Jadhav and Savita Goswami; Year: 2011, Country: India	Paediatric Palliative Care: Theory to Practice	The review article outlines some of the salient features of paediatric palliative care which are relevant to all professionals caring for children with life-limiting illnesses in their practice	Review Article	(1) A majority of parents did not wish to discuss the disease or dying with the child, citing anticipated distress or young age as reasons for non-disclosure. (2) Parental anxiety and collusion were the major barriers to formal support or open communication with the children	(1) Need for support groups for caregivers. (2) Need for advocacy and networking in paediatric palliative care
Author: Sheryl Jyothi Cornelio, Baby S Nayak and Anice George, Year: 2016, Country: India	Experiences of Mothers on Parenting Children with Leukaemia	The objective of this study was to explore the experiences of mothers in parenting children with leukaemia	(*n*=10) a purposive sample of mothers of children between the age group of 1–16 years diagnosed with leukaemia and undergoing chemotherapy. A qualitative approach with phenomenological design. Semi-structured interview	Emotional responses of mothers after hearing the initial diagnosis ranged from shock, denial to grief. The themes derived are the pivotal moment in life, the experience of being with a seriously ill child, having to keep distance with the relatives, overcoming the financial and social commitments, responding to challenges, the experience of faith as being key to survival, health concerns of the present and future and optimism	Understanding the emotional experiences of mothers helps the nurses in providing holistic care to a child with leukaemia
Author: Asmita Das, Bhavneet Bharti, Prahbhjot Malhi and Sunit Singhi Year: 2019, Country: India	End-of-Life Milieu of Critically Sick Children Admitted to a Paediatric Hospital: A Comparative Study of Survivors versus Non-survivors	This study aimed to describe the end-of-life (EOL) milieu among caregivers of children who died in the hospital and to compare their psychosocial, spiritual and financial concerns with caregivers of children who survived	Sixty caregivers of children (30 survivors and 30 non-survivors), admitted in the paediatric intensive care unit and the general paediatric unit, were recruited over 1 year. Mixed qualitative methods (observations, semi-structured questionnaire and rich narrative interviews) were used to collect information from parents on EOL care perspectives	(1) The caregivers of non-survivors versus survivors showed no significant differences as regards optimal care (76.67% vs. 56.67%), social support (76.6% vs. 66.67%) and frequent recitation of scriptures (30.77% vs. 45.83%). (2) Mean medical expenditure among children receiving EOL care was Rs. 40,883 (range: Rs. 800–5 lakhs), (3) Medical insurance was reported by only a minority of the cases (5%) (4) The importance of communication and the need for emotional, social and financial support was highlighted. (5) EOL decision was taken in only two of the non-surviving children	(1) The study unmasked the unmet financial, psychological, religious, and social needs to improve the end-of-life care of hospitalized children with a critical illness. (2) Calls for sensitization of the healthcare providers to optimize their care

(Contd...)

Table 2: *(Continued)*

Author and Year, Country Affiliation	Title	Aim	Sample size and Method	Findings	Conclusion
Author: Sneha Magatha Latha, Julius Xavier Scott, Satish Kumar, Suresh M Kumar, Lalitha Subramanian, and Aruna Rajendran, Year: 2016, Country: India	Parent's Perspectives on the End-of-life Care of their Child with Cancer: Indian Perspective	This study aimed to identify the symptoms (medical/social/emotional) that most concerned parents have at the end-of-life care of their cancer child and to identify the strategies parents found to be helpful during this period	Parents of 10 children who lost their child to cancer were interviewed with a validated prepared questionnaire	(1) Toward death, dullness (30%), irritability (30%) and withdrawal from surroundings (10%) were the most common symptoms encountered. (2) About 30% of the children had feared being alone. (3) About 50% of the children had the fear of death. (4) Pain, fatigue, loss of appetite were the main distressful symptoms that these children suffered from their parent's perspective. (5) Though the parents accepted that the child was treated for these symptoms, the symptom relief was seldom successful	The study concluded that at the end of their child's life, parents value obtaining adequate information and communication, being physically present with the child, preferred adequate pain management, social support and empathic relationships by the health staff members
Author: Manjusha Nair, Lidiya T Paul, PT Latha and Kusumakumary Parukkutty, Year: 2017, Country: India	Parents' Knowledge and Attitude Regarding Their Child's Cancer and Effectiveness of Initial Disease Counselling in Paediatric Oncology Patients	The objective was to examine parent's knowledge, attitude and psychosocial response regarding their child's cancer and treatment after initial disease counselling by the doctor	Structured questionnaire based study of 43 mothers of newly diagnosed paediatric cancer patients undergoing treatment in paediatric oncology division	(1) More than 80% of mothers knew the name of their child's cancer, the type of treatment received by the child and the approximate duration of treatment. (2) 93% knew regarding painful procedures and 84% of mothers reported knowledge about chemotherapy side effects. (3) Hope of cure and satisfaction with treatment was reported by 90% of mothers. (4) 81% of mothers reported high levels of anxiety and 66% worried regarding painful procedures. (5) As high as 60% of parents were afraid to send their child outside to play and 40% were afraid to send their child to school. (6) 40% of mothers wanted more information regarding child's higher education, married life & fertility. (7) On statistical analysis, mothers' age, educational status, or family background did not influence their knowledge and attitude	Relevant information about a child's cancer and treatment can be imparted effectively even to mothers with school-level education. This knowledge helps to instil a hopeful attitude, confidence and satisfaction in parents. Anxiety and fear related to cancer persist in mothers even after the initial stress period is over. Pain related to injections and procedures is a major concern in parents. Involvement of counsellor in the treating team is desirable to overcome these problems

(Contd...)

Table 2: *(Continued)*

Author and Year, Country Affiliation	**Title**	**Aim**	**Sample size and Method**	**Findings**	**Conclusion**
Author: Tulika Seth, Year: 2010, Country: India	Communication to Paediatric Cancer Patients and their Families: A Cultural Perspective	Aim of the study was n to fill the void in cultural communication parents were interviewed	25 consecutive parents of paediatric cancer patients (acute lymphoblastic leukaemia) in the age group 10-18 years (mean age 13 years) were interviewed	(1) Majority of the families had not wanted their children (even aged 18 years) to be informed of the diagnosis [65%, (15/23)], (2) 35% had been open to informing the child about their diagnosis. (3) 95%, (22/23)] felt the child should not make any decision about the treatment. (4) [60%, (14/23)] felt the child should not even be informed about side effects of therapy and especially about long term effects. (5) 100% preferred that the doctors to give the information to the child should the diagnosis and prognosis be told. (6) The parental reservations were that they had not been given sufficient prior knowledge of what was to be done (counselling) and would have liked additional time to prepare themselves and would have wanted the information to have been given to the child at a later date (after treatment started and not before as done by physicians) (7) The parental responses showed that the decision was mostly the domain of the parents -20 felt only parents should decide, seven doctors alone and four families stated that both the doctor and parent should decide, none of the parents felt the child should take part in this decision making process	Training programs in communication skills should teach doctors how to elicit patients' preferences for information. Systematic training programs with feedback can decrease physicians stress and burnout. More research for understanding a culturally appropriate communication framework is needed

(Contd...)

Table 2: *(Continued)*

Author and Year, Country Affiliation	Title	Aim	Sample size and Method	Findings	Conclusion
Author: Rajesh Kumar Singh, Aditya Raj, Sujata Paschal and Shahab Hussain, Year: 2015, Country: India	Role of communication for paediatric cancer patients and their family	The aim was to fill the gap in area of cultural communication, a study questionnaire was administered to consecutive families of children receiving chemotherapy at a large, north Indian referral hospital to elicit parental views on communication	25 consecutive parents of paediatric cancer patients in the age group 1–14 years were interviewed. All the children were on treatment for their disease at our hospital for at least 6 months (range 6–38 months)	Most parents had a protective attitude and favoured collusion; however, appreciated truthfulness in prognostication and counselling by physicians; though parents expressed dissatisfaction on timing and lack of prior information by counselling team	Training programs in communication skills should teach doctors how to elicit patients' preferences for information. Systematic training programs with feedback can decrease physicians stress and burnout. More research for understanding a culturally appropriate communication framework is needed

- Financial support.

Spiritual perspective

- Spirituality
- Faith in God
- Beliefs.

All identified themes discussed in different papers are summarized in [Table 3].

Psychological perspective

Parenting stress, or stress directly related to the role of the parent, is important to understanding family dysfunction and psychopathology.[21] Parenting stress may also affect a child's health-related outcomes as it could potentially interfere with the management of a child's chronic condition.[22] In addition, parents of children with life-limiting illnesses are vulnerable to negative social, psychological, physical, relational, individual, and financial issues and are more likely to have depressive symptoms,[23] these additional stresses adversely affect the decision-making of the parents and interfere with their roles as parents.[24] Hence, it seems important to understand the psychological perspectives of parents to better address the decision-making and communication issues.

All nine studies emphasized parent's psychological perspectives in varying degrees [Table 3].

Parental needs

A study conducted by James and Johnson in 1997[25] aimed at studying parents' perceptions of their needs while their child was dying of cancer. Three needs were identified: (1) the need to retain the responsibility of parenting their dying child; (2) the need for caring and connectedness with health care professionals; and (3) the need to have the child recognized as special while retaining as much normality within the child's and family's lives as possible.[25] Along with it, culturally appropriate communication,[4] diagnostic and prognostic communication[8] were reported as the primary needs, accompanying social support, bereavement support, and financial support.[17] And finally, counselling needs and psychological support were found to be crucial needs of parents.[26]

These pre-existing, unmet needs may complicate care and decision-making.[24] Hence, understanding parental perspectives of what they need and what they value is crucial to communication and decision-making.

All studies were focused on parental needs where the need for effective communication was a recurring need followed by the need for social support, emotional support, along with financial support. Spiritual needs and Bereavement support were also recorded as important needs.

Parental concerns

Parental attitudes hinder open communication with dying children in India, with a need for research to explore these concerns of parents.[27] In a recent study conducted by Tutelman *et al.*,[28] parents' concerns clustered into four main themes: (1) ensuring that their child's remaining days were

Table 3: Review of parental perspective reported in studies, (Continued from Page 31 till 35).

Study	Year	Psychological Impact	Needs	Concerns	Parental Attitude	Cultural Perspective	Spiritual Perspective	Financial Perspective
Seth T. Communication to Paediatric Cancer Patients and their Families: A Cultural Perspective	2010	Reported that even after therapy parents reported stress in communicating about cancer to their children, hence showed apprehension in discussing the diagnosis with the child delaying the process	1. Need for information and knowledge of Child'sof diagnosis and prognosis before the treatment started. 2. Need for better communication from the care team	Treatment outcomes, Quality life	• Parents did not want to involve their children (even aged 18 years) to be informed of the diagnosis, prognosis or therapy effects • Did not want the child to be involved in decision making • If the diagnosis, prognosis and other information was to be told to the child, 100% preferred that the doctors to give the information to the child • Almost all parents didn't approve the idea of shared decision making and thought decision making to be the domain of parents	• Parents had reservations about western medicine, feeling they are too strong or too hot for children • They also use complementary medicines sometimes without informing it to the treating doctor • The parents were often unwilling to undertake any type of major surgery or treatment fearing it would compromise on the female child's physical appearance or lead to permanent disability, for example, deformity, loss of vision; as it will hamper future prospects of marriage • If therapy were likely to cause infertility parent had concerns of societal stigma for the child when she grows up • Western concepts of telling the cancer patient about the disease and involving the patient/or family in treatment making decisions are alien to the Indian culture and may add to the patient's distress	Not mentioned	Not mentioned

(Contd...)

Table 3: *(Continued)*

Study	Year	Psychological Impact	Needs	Concerns	Parental Attitude	Cultural Perspective	Spiritual Perspective	Financial Perspective
Muckaden, M., Dighe, M., Balaji, P., Dhiliwal, S., Tilve, P., Jadhav, S., & Goswami, S. Paediatric palliative care: theory to practice. 2011	2011	(1) Reported Psychological distress and stress of parents, issues with coping and risk of burnout (2) Parental anxiety and collusion were the major barriers to formal support or to open communication with the children	• Need for social support • Economic support • Bereavement support	• Quality of Life • Symptom management • Characteristics of death	• Majority of parents were uncomfortable discussing the disease with the child and felt that it would be difficult to talk about dying • Parents did not wish to discuss the disease or dying with the child, citing anticipated distress or young age as reasons for non-disclosure	Cultural perspective effecting decision making was reported by parents in this study	Spiritual perspective of caregivers reported to some extent	Financial burden reported
Singh, R. K., Raj, A., Paschal, S., & Hussain, S. Role of communication for paediatric cancer patients and their family. 2015	2015	Reported that even after therapy parents reported stress in communicating about cancer to their children, hence showed apprehension in discussing the diagnosis with the child delaying the process	• Need for better communication • Need for diagnostic and prognostic information	NA	• Parents showed negative response related to delivery of diagnostic information to child • All parents felt that the child should not make any decision about the treatment • Parents felt the child should not even be informed about side effects of therapy and especially about long-term effects • If the diagnosis, prognosis and other information was to be told to the child, 100% preferred that the doctors to give the information to the child • Parents didn't believe in shared decision-making	NO emphasis on cultural perspective	NA	NA

(Contd...)

Table 3: *(Continued)*

Study	Year	Psychological Impact	Needs	Concerns	Parental Attitude	Cultural Perspective	Spiritual Perspective	Financial Perspective
Cornelio, S. J., Nayak, B. S., & George, A. Experiences of Mothers on Parenting Children with Leukaemia	2016	• Mothers expressed • Shock and disbelief, doubt if the correct diagnosis was established • Deep sadness • Grief • And to gradual adjustment to the diagnosis over time • Coping through optimism and spirituality • Fear of seclusion from society and isolation	• Financial needs • Spiritual needs • Social support and emotional support • Need for better treatment support	• Concerns whether a correct diagnosis had been established • Concerns for future of child's treatment • Quality of life of the child • Treatment outcomes	NA	NA	Strong faith in God for meaning and purpose were reported by mothers	The financial burden was one of the major issues
Latha, S. M., Scott, J. X., Kumar, S., Kumar, S. M., Subramanian, L., & Rajendran, A. Parent's Perspectives on the End-of-life Care of their Child with Cancer: Indian Perspective	2016	• Parents reported guilt due to the worsening condition of the child • Reported distressing symptoms of children during end-of-life • Struggled with decision-making during end-of-life and aggressively continued treatment	Communication needs to be the central theme	Characteristics of death being a primary concern	Parents were the sole decision-makers. Some parents opted for alternative medicines and even after understanding that their child's condition is not curative, they aggressively pursued treatment in the hope of a miracle	NA	NA	NA

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Table 3: *(Continued)*

Study	Year	Psychological Impact	Needs	Concerns	Parental Attitude	Cultural Perspective	Spiritual Perspective	Financial Perspective
Mohan, G., Scott, J. X., Nasrin, R., Sneha, L., Manohar, R., Subramanian, L., Narayani, S., & Rajendran, A. First Counselling Revealing the Diagnosis of Childhood Cancer: Parent Preferences From an Indian Perspective. 2016	2016	Psychological distress was reported since it was the first counselling session on breaking the bad News	• Need for counselling • Communication needs • Need for information • Social support • Resources for financial support	NA	Parents did not want to reveal the diagnosis to the child	NA	NA	After the first counselling one of the major concerns and important questions asked by parents were the availability of financial support and resources
Nair, M., Paul, L. T., Latha, P. T., & Parukkutty, K. (2017). Parents' Knowledge and Attitude Regarding Their Child's Cancer and Effectiveness of Initial Disease Counselling in Paediatric Oncology Patients	2017	• Mothers reported being preoccupied with thoughts regarding their child's disease and having high levels of anxiety • Were worried regarding painful injections and procedures • Anticipatory grief and fear for treatment outcomes	• Need for more information • Better treatment support • Counselling needs	• Quality of Life • Symptom management • Treatment outcomes for future	Mothers did not want to reveal the diagnosis to the child	Reported apprehension for fertility and marriage	NA	NA

(Contd...)

Table 3: *(Continued)*

Study	Year	Psychological Impact	Needs	Concerns	Parental Attitude	Cultural Perspective	Spiritual Perspective	Financial Perspective
Chivukula, U., Kota, S., & Nandinee, D. Burden Experience of Caregivers of Acute Lymphoblastic Leukaemia: Impact of Coping and Spirituality	2018	Psychometric tool Brief cope was administered and reported coping strategies, caregiver's burden, substance abuse, emotional distress and behavioural impact of fathers and mothers separately	Spiritual and Psychological needs	NA	NA	Reported to some extent but not specifically.	Spirituality was a significant predictor of emotional, physical, developmental and social burden, a major coping mechanism for mothers	Reported to some extent but not specifically
Das, A., Bharti, B., Malhi, P., & Singhi, S. End-of-Life Milieu of Critically Sick Children Admitted to a Paediatric Hospital: A Comparative Study of Survivors versus Nonsurvivors	2019	Psychological distress of parents and emotional experiences recorded to some extent	Parent's reported need for • Communication • Emotional, social and financial support • Empathy and spirituality • Need for honesty in information provided, manner of communication and time constraints	Parents expressed concern that their concerns regarding treatment support, their perspectives, goals and decision making were not addressed adequately	NA	Reported to some extent but not specifically	• Strong faith in God and Rituals reported • Faith in astrology and healers	• Majority of the parents reported borrowing money • Loss of wages was reported by majority • No insurance • Greater degree of financial burden • And financial burden leading to considering of abandonment of treatment

spent living well physically, emotionally, and socially; (2) uncertainty regarding their child's diagnosis, prognosis and treatments; (3) their child's death (e.g., the process of dying and when it will occur); and (4) the family, including the impact of the child's illness and death on siblings and wanting to cherish as much time together with family as possible.[28] There could be a host of such concerns identified in parents and could be summarized into parental concerns for the quality of life, symptom management, characteristics of death, end of life decision-making, treatment and treatment outcomes, and financial concerns among others.

Six out of nine studies reported parental concerns expressed by caregivers,[4,17,18,20,26,29] with quality of life of the child being a recurring concern followed by treatment outcomes, future of the child, characteristics of death, treatment support, and financial support. One study reported a major parental concern being their concerns; their goals, perspective, decision-making, and treatment support concerns not being addressed adequately.[20]

Parental attitude

The UN Convention for the rights of a child (Assembly resolution 44/25 of 20 November 1989 entry into force 2 September 1990, following article 49) recognized a child's right as a decision-maker.[30] While Feudtner in his study explained that in paediatric care, decision-making is triadic, involving the parents, the kid, and the clinician.[5] Indian parents might have a different almost negative attitude toward involving the child in decision-making, or shared decision-making.

Six studies reported parental attitude out of which three studies pointed out that parents have a protective attitude toward children,[4,17] favoured collusion,[4,8,17] and all six papers reported parents did not want to reveal diagnosis, prognosis, or treatment procedures and outcomes to their children.[4,8,17,26,29,31]

Cultural perspective

Dealing with the potential loss of one's child is a terrible experience across cultures[32] and while 'the right to know' is accentuated in bioethics, in certain cultural contexts, health professionals fear communicating the bad news causing the patient or families not to receive the news directly.[33] However, the literature suggests that cultural influences may further complicate the appropriate integration of paediatric palliative care making it a frequently occurring barrier to adequate paediatric palliative care as reported by health care providers.[34] For example, Indian parents have reservations about western medicine, feeling they are too strong or too hot for children, often leaning toward alternative medications without informing the treating Doctor,[4] frequently unwilling to undertake major life-saving surgeries or treatments fearing they would compromise their child's (female) physical appearance or lead to permanent disability, infertility, deformity, loss of vision subsequently hampering the future prospects of marriage.[4] Hence, the care team needs to understand these cultural perspectives and barriers so to make the communication more fluid and aid important decision-making among caregivers. Only one study emphasized the cultural perspectives of parents,[4] while other studies touched the subject briefly and eluded swiftly without putting much significant emphasis on it probably because the focus of the studies was on other aspects of parental perspectives.

Spiritual perspective

How religion, spirituality, and faith play an important part in decision-making across cultures is a question that researchers and clinicians need to address in paediatric palliative care.[35] Different religions and faiths may have different practices in illness, death, and dying. For instance, in Buddhism family's presence is considered important, they may chant mantras as infant/child becomes seriously ill and would not touch the child's body after death,[36] while in Catholicism sacrament of the sick is done with the anointing of oil, communion and final blessing by a priest.[37] In Hinduism, it is considered ideal to be surrounded by family and friends who chant sacred hymns and say prayers or chant the dying person's mantra, when death is near, the family spiritual leader is asked to conduct final rites and cremation[38] whereas in Islam the body is washed 3 times, Muslim burial is done within 24 h and cremation is prohibited.[39]

Different communities across the globe have different beliefs in regards to illness with diverse end-of-life practices. In Buddhist, Hindu, or Confucian faiths illness and suffering are sometimes attributed to bad karma,[40] and these communities view suffering as a mechanism for the atonement of sins committed in a past life. South Asian communities often attribute illness and suffering to sins committed in a previous life,[41] while avoidance of suffering transfers the pain to the next life.[42] Actions taken at the end of life are sometimes associated with advanced bereavement reactions. For example, in the Chinese culture, bad death is often associated with a curse making parents overwhelmed with guilt if they cannot facilitate what they believe to be a good death for their child.[43] Hence, conducting spiritual assessments with the child and family is an essential element of paediatric palliative care.[44]

In the systematic review, three out of nine papers emphasized parental perspectives in spiritual terms.[18-20] Strong faith in God established meaning and purpose among mothers,[18] in another study spirituality was a significant predictor of emotional, physical, developmental, and social burden and was a major coping mechanism for mothers in comparison to fathers[19] whereas one study pointed out parent's inclination toward miracle healers and astrology.[20]

Financial perspective

About 25% of cancer patients consume most or all of their savings in their cancer treatment,[45] and India being a developing country the delivery of affordable and reasonable cancer care is one of the greatest public health challenges, breaking the back of the families with catastrophic out-of-pocket expenditures.[46] A high financial burden with no proper financial support may lead caregivers who come from lower economic backgrounds to desperation. They may find it hard to continue treatments for their children, sometimes leading to the abandonment of treatment where the rate of abandonment is between 17 to 62% in Tertiary centres.[47]

Three papers specifically focused on the financial perspective of parents [Table 3].[18,20,30] The first question asked by caregivers after the first counselling session of breaking the bad news of cancer diagnosis was whether they may get any financial help and if so, from where (30 Mohan, 2016). Parents expressed their grief of the loss of lands to bear treatment costs along with burrowing money and loss of wages.[20] Most of the parents did not have insurance and at times considered abandoning the treatment.[20]

DISCUSSION

It was evident that the need for proper communication was an important issue that frequently emerged, but understanding parental perspectives are central to the fulfilment of the need for communication. Parents of children with life-limiting illnesses such as cancer assume many roles for their children such as a nurse, coordinator, financial manager, medical decision-maker, advocate, relationship manager, transporter, and educator along with the role of being a typical parent.[48] Caregiving, hence, could be divided into five basic types of support: personal, informational, medical, instrumental, and emotional,[49] among which the task of decision making is the one that requires a lot of mental energy and time,[50] frequently putting the parents in a tough position such as subjecting their children to painful procedures and treatment without wanting to, quite opposite to their role as typical parents which demands that they protect their child from pain and discomfort. With such a difficult decision-making process and the burden of assuming many roles as a caregiver, the parents may skip on self-care, be vulnerable to emotional distress and find themselves socially isolated.[51] Considering the fact that the wellbeing of the parent directly affects the child, addressing parental needs and concerns is central to paediatric palliative care.[50]

Hence, health-care providers need to assess their parental needs, concerns and understand their perspectives so as to support them by helping them with respite care, proper communication, care coordination, aid in decision-making, relief in pain and distress, providing emotional and social support.[50] It appears that more investigation is required into the parental perspective's domain. Understanding parental perspectives in regard to their needs, concerns, attitudes, and their psychological, spiritual, and financial concerns would aid care providers to deliver empathetic and effective communication, which furthermore assists in decision-making, has the potential to foster trusting relationships, provide useful information and anticipatory guidance along with supporting caregivers and patients according to their needs.[50,52]

Understanding the parental perspectives would also aid in designing communication tools akin to the systematic conversation guide that is culturally appropriate and fit to the Indian context.

CONCLUSION

The systematic review of parental perspectives in paediatric palliative care in the Indian context points toward a gap in the literature, hereafter more research is required into the domain of understanding parental perspectives. There is also seems a necessity for validated tools, checklists, and psychometric questionnaires for the assessment of these perspectives in various domains: spiritual, financial, psychological, cultural, and social.

Declaration of patient consent

Patient's consent not required as there are no patients in this study.

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Conflicts of interest

There are no conflicts of interest.

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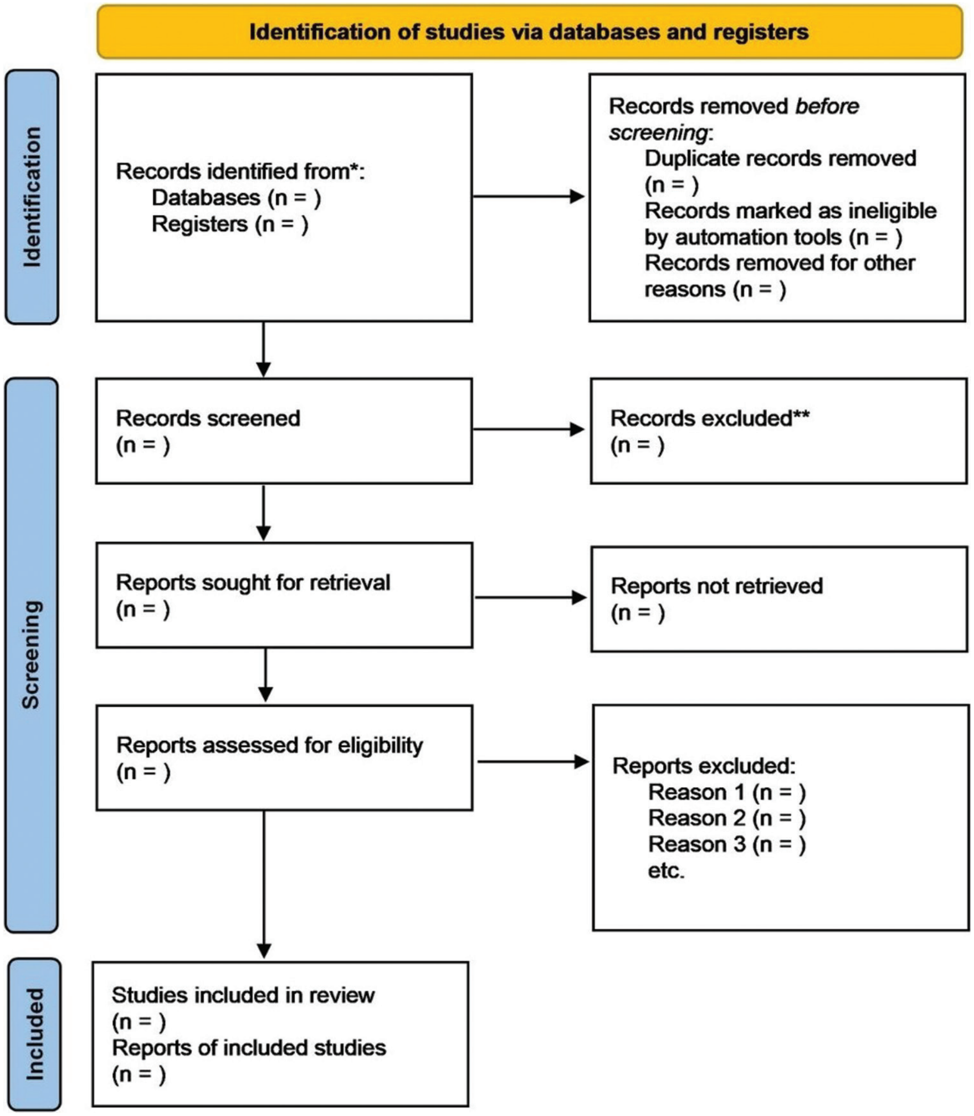
APPENDICES



Appendix A: PRISMA Guidelines.

PRISMA 2020 flow diagram for new systematic reviews which included searches of databases and register only. From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. DOI: 10.1136/bmj.n71. For more information, visit: http://www/prisma-statement.org/