



Original Article

# Issues Related to Children-Faced by Armed Forces Families When Caring for Patients in Palliative Care – A Qualitative Study

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## ABSTRACT

**Objectives:** Access to palliative care is limited, especially in rural India. Children needing care by palliative teams may themselves be patients, or siblings and children of patients. Armed forces families face characteristic lifestyle challenges – frequent transfers, living in difficult and remote areas, serving personnel staying apart from families for long periods – very different from issues faced by civilians. Military service increases the risk of psychosocial burden for serving personnel as well as families. Most depend on private and state medical services for palliative care so it is important for the palliative community to understand their issues. This study aimed to explore the issues related to children – faced by armed forces families when caring for patients in palliative care.

**Material and Methods:** Qualitative study based on thematic analysis of semi-structured interviews with caregivers – either serving personnel or their dependents, in three centres.

**Results:** Analysis of the 15 interviews showed that armed forces families face complex challenges related to children when caring for the palliative patient due to frequent movement, lack of paediatric palliative services in far-flung areas, disruption of the continuity of care, social isolation, language, and cultural barriers when living in non-native areas, inability to build and access family and community support and financial burden due to restrictive reimbursement policies.

**Conclusion:** Although medical and administrative support within the organisation provides a cushion, wives have to manage alone in the father's prolonged absence, and safety is a concern for children when living outside the campuses and serving personnel report guilt, anger, and helplessness at not being present when needed. Awareness of these issues can enable palliative workers to provide more meaningful support tailored to the needs of service families.

**Keywords:** Children, Palliative, Armed forces, Caregivers, Qualitative

## INTRODUCTION

Palliative care is still an evolving concept in India. Access to palliative care, pain relief, and end-of-life care is limited, especially in rural areas. Children needing care by palliative teams may themselves be patients, or siblings and children of patients in palliative care. Paediatric palliative care has a different spectrum of diseases than adults – with intense and complex psychosocial demands placed on the caregivers. In the armed forces, which have their unique lifestyle and challenges, these add up to create situations that may differ vastly from those in the civilian setup. Frequent relocations with serving personnel staying apart from families for most

of their careers are the defining features of life in the armed forces. Difficult conditions of living and working in remote and far-flung areas, the omnipresent fear of disability and death during deployment, and limited days of leave from duty lead to stress for both the personnel and the families. Evidence shows that military service increases the risk of psychosocial burden not only for serving personnel but also for their spouses and children as well.<sup>[1]</sup> The enforced family separations lead to intrapsychic conflicts for wives and children of serving fathers absent from home, resulting in predominant anger, mourning, and guilt, as seen in grief reactions, often escalating to crises.<sup>[2]</sup>

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Received: 08 March 2023 Accepted: 26 September 2023 Epub Ahead of Print: 03 November 2023 Published: 11 November 2023 DOI: 10.25259/IJPC\_58\_2023

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Families may stay in their native places or sometimes in campus accommodations, which are few and allotted for a limited period only. They face the same lack of access to palliative care and pain relief in rural areas as other Indians. Since families in native areas depend on private and state medical services for their palliative needs, it is important for healthcare workers to be aware of and understand their issues to be able to offer meaningful support.

There is a paucity of literature on palliative care in the Indian armed forces. A literature search using the terms 'caregivers', 'armed forces', and 'palliative care in India' in PubMed, EMBASE, CINAHL, and MEDKNOW revealed only three articles related to palliative care in the Indian armed forces.<sup>[3-5]</sup> This study was, therefore, undertaken to address the knowledge gap.

This study aimed to explore the issues related to children – faced by armed forces families when caring for patients in palliative care.

## MATERIAL AND METHODS

This is a qualitative study based on semi-structured interviews with caregivers of patients with palliative needs, conducted after obtaining informed consent and necessary ethical approval. The study sample was drawn from three secondary-level hospitals (Delhi, Jalandhar, and Jodhpur) of India's Border Security Force (BSF) – an International border-guarding armed force. Caregivers of patients registered in the previous 3 years were listed. Random lots were drawn to select names. The inclusion and exclusion criteria are shown in [Table 1].

Informed consent from participants was taken after giving all information about the study. Written information sheets

were given, both in English and Hindi. Participants could refuse participation at any time without any penalty or loss of benefits entitled otherwise; important because armed forces are a 'vulnerable research population'.<sup>[6]</sup> A subject could withdraw after written or verbal intimation and would be replaced by another from the list of possible participants by drawing lots. The subject's participation could be terminated by the investigator if the participant was physically or mentally incapacitated during the research. A 'distress protocol' was established to support distressed subjects.

Participants were invited through letters and email. Fifty letters were sent out. Twenty-one caregivers agreed, and six dropped out later. Two were transferred, three proceeded on temporary duty and one did not want to revisit the grief of bereavement. The interviews were conducted after written consent, recorded in a digital recorder, and transcribed verbatim by the researcher. The consent form [Table 2] was drafted with the help of the research supervisor.

The interviews [format in Table 3] were conducted at the residences of the interviewees at the date and time of their preference, pre-decided through phone or email. In the beginning, asking questions about personal details helped break the ice, build rapport, and collect basic information. Non-verbal communication was observed and noted. The average duration was 90 min. It was ensured that all the general themes had been mentioned and the interviewee got the opportunity to comment on all of them. Any additional information such as interruptions, silences, and new themes was noted. Transcription was done by the investigator, allowing exact transcription as well as analysis of finer nuances and non-verbal communication, which would have been lost if someone else had done

**Table 1:** Inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
<p>Adult carers (aged more than 18 years) of patients with the following conditions: Carers – defined as <i>'People who may or may not be family members, are lay people in a close supportive role, who share the illness experience of the patient and undertake vital care work and emotional management'</i>.<sup>[2]</sup> Palliative care and caregiving by family/care by the personnel from the unit are considered starting from the time of diagnosis.</p> <ul style="list-style-type: none"> <li>• Cancer</li> <li>• HIV/AIDS</li> <li>• COPD</li> <li>• Chronic renal failure</li> <li>• Chronic liver failure</li> <li>• Paraplegia after spinal cord injury</li> <li>• Paraplegia or hemiplegia after cerebro-vascular accident</li> <li>• Children with congenital malformations</li> <li>• Cerebral palsy.</li> <li>• Either serving personnel or their dependent family members</li> <li>• Registered within the last 3 years.</li> </ul>	<p>Those who were:</p> <ul style="list-style-type: none"> <li>• Not willing to participate</li> <li>• Lacking capacity</li> <li>• Not able to communicate effectively due to: <ul style="list-style-type: none"> <li>• Disability</li> <li>• Lack of common language for communication.</li> </ul> </li> <li>• Those whose relative died within the last 1 year</li> </ul>

HIV: Human immunodeficiency virus, AIDS: Acquired immunodeficiency syndrome, COPD: Chronic obstructive pulmonary disease

**Table 2:** Consent form for participants.

Informed consent form to participate in a dissertation study

Study Title: \_\_\_\_\_

Study Number: \_\_\_\_\_

Subject's Initials \_\_\_\_\_ Subject's Name \_\_\_\_\_

Date of Birth/Age: \_\_\_\_\_

Please Initial

Box (Subject)

(i) I confirm that I have read and understood the information sheet dated -----  
\_\_\_\_\_ for the above study and have had the opportunity to ask questions.

(ii) I understood that my participation in the study is voluntary and that I am free to withdraw at any time' without giving any reason, without my medical care or legal rights being affected.

(iii) I understand that the sponsor of the clinical trial, others working on the sponsor's behalf; the Ethics Committee and the regulatory authorities will not need my permission to look at my health records both in respect of the current study and any further research that may be conducted in relation to it, even if I withdraw from the trial. I agree to this access. However, I understand that my identity will not be revealed in any information released to third parties or published.

(iv) I agree not to restrict the use of any data or result that arises from this study Provided such a use only for scientific purpose (s)

(v) I agree to take part in the above study.

Signature or Thumb impression of the subject/legally acceptable Representative: \_\_\_\_\_

Date \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_

Signatory's Name: \_\_\_\_\_

Signature of the Investigator: \_\_\_\_\_

Study Investigator's Name: \_\_\_\_\_

Signature of the Witness \_\_\_\_\_ Date: \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_

Signature of the Witness \_\_\_\_\_ Date \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_

it. The translation was done into English from Hindi and scripts were randomly checked by a Hindi teacher proficient in both languages. After 12 interviews, new themes were still emerging so interviews were continued till data saturation occurred at 15 interviews. These were recorded without any names or identifying features, allotted serial numbers and stored in a computer, under triple-layer security.

### Analysis

Each transcript was read several times. The important comments, thoughts, and reflections highlighted and noted down in the margins formed the descriptive codes. These were colour-coded and grouped into categories in chronological order. The categories were grouped to look for themes. Superordinate themes were identified by identifying common points between subthemes. The transcripts were then read twice more to ensure that the themes were actually representative of all the 15 interviews. Finally, master themes and sub-themes were assembled together.

### Reflexivity statement

The investigator has served in the BSF for more than two decades. This provides insight which is difficult for

outsiders to achieve, but is bound to introduce bias and preconceptions – avoided by recording and transcribing the data accurately and not asking leading questions. Selection bias and channelling bias, more likely when the patient assignment is performed by medical personnel were avoided by randomisation through drawing lots. Interviewer bias and recall bias were avoided by following the same semi-structured format of the interview throughout. Member checking was done for internal validity.

## RESULTS

### Demographic characteristics

#### Age distribution

All subjects were young (<45 years).

#### Sex

There were nine males and six females.

#### Predominantly rural

Ten caregivers belonged to rural areas.

#### Rank-wise distribution

Officers/officers' families – 4, subordinate officers – 1, other ranks/their families – 10.

**Table 3:** Questionnaire for semi-structured interview.

Name
Sex
Age
Address
Educational qualification
Occupation
Address
Telephone no
Email
Name of patient
Relationship to BSF personnel
IRLA/Regiment no
Unit
Diagnosis
Year of diagnosis
Year of death
<ul style="list-style-type: none"> <li>• The diagnosis and its effect on the patient and family</li> <li>• Awareness of the prognosis and its effect on the patient and the family</li> <li>• Challenges while caring for the patient</li> <li>• Challenges due to distance between the place of posting, hospital, and home.</li> <li>• How much of the decision-making regarding the treatment or place of care was informed/participative?</li> <li>• How did they feel about the unit personnel caring for their loved one?</li> <li>• What were their needs for information?</li> <li>• To what extent were these needs met?</li> <li>• What was their experience of caring for the patient at home?</li> <li>• What was their experience regarding the availability of medicines, doctors, nurses, other healthcare workers, equipment</li> <li>• What was their experience of travelling to the hospital?</li> <li>• What were the financial issues during this period?</li> <li>• What were the psychosocial and spiritual issues?</li> <li>• Was there any support available? If yes, who provided it?</li> <li>• Was the place of care discussed with the patient or family?</li> <li>• In case of death, was the place of death according to their wishes?</li> <li>• What grief and bereavement support did they receive?</li> <li>• Did the organisation support their needs? If yes, how?</li> <li>• What suggestions would they give for the care of similar patients?</li> <li>• Anything else they think is important and want to share.</li> </ul>

### **Other family members in forces**

Seven of the 15 interviewees had their parents or siblings also serving in the armed forces.

### **Grief during narration**

Ten caregivers were in tears during interviews.

### **Issues reported**

Lack of access to palliative care and pain relief especially in rural and far-flung areas where BSF is deployed [Table 4]. Often, the wife staying alone, was unable to travel to the city

as cultural barriers prevented travelling without a chaperone and also because it is physically impossible to transport a bed-ridden child alone. Road connectivity, transportation, and access to opioids are major hurdles in remote areas.

Interrupted continuity of care and inability to build up and access social support systems due to frequent relocations is a major cause of anxiety and stress. Leave from duty is limited to 60 days earned and 15 days of casual leave. This too may not always be granted when needed due to operational commitments. Travelling from distant places also consumes precious days.

Different expectations, priorities, and levels of involvement of family members lead to interpersonal conflict.

Children left alone-interrupted studies and safety concerns: Most caregivers had young children. If the mother had to care for a hospitalised patient, they had to be left behind. The children who had to look after sick family members in the absence of the father had to manage household work – cooking, cleaning, and washing on their own, which adversely affected their studies. The safety of these children was a major concern if living alone outside campuses, especially fear of sexual abuse in the case of girls and the intellectually disabled. Those in joint families fared better than those in nuclear families living outside the campus.

Social isolation: Loneliness is a major problem, especially for mothers of paediatric patients who had to give up both work and socialising. Caregivers of children with cerebral palsy or locomotor disability reported difficulty in travel from one place of posting to another, for treatment or vacations because of a lack of equipment and disabled-friendly transport and public areas.

Psychological issues: Guilt, anger, helplessness, frustration 'at not being there' for families, and worry for the children's future after their death.

Spiritual distress: Reported by 13 subjects, was significantly more conspicuous in parents of paediatric patients. The notions of 'Karma' and fate are mentioned often. Eight caregivers found their faith helpful in difficult times.

Information needs: Lack of communication from hospital staff regarding paediatric patients prevented joint decision-making. Children were not given information by families even when they asked as they were considered too young to understand and parents did not want to burden them.

Financial issues: Were reported by 12 caregivers. In the absence of BSF hospitals in the villages and distant, overcrowded state government hospitals, patients prefer the private sector even if it means spending out-of-pocket. However, private treatment is not reimbursable. Diapers, supplements, vocational rehabilitation, special braces, and equipment, even though essential, are also not reimbursed. Others such as hearing aids and wheelchairs are subject to reimbursement limits, adding to the financial burden.

Support within the organisation: Families staying within

**Table 4:** Issues faced.

Lack of access to palliative care in remote areas.	Caregiver 9, Page 2, Line 29
Frequent relocations lead to a lack of continuity of care	Caregiver 4, Page 22, Line 11–13
Inability to build up and access social support due to frequent transfers	Caregiver 8, Page 21, Line 29–31
Differing expectations and priorities of care causing inter-personal conflict	Caregiver 4, page 16, Line 25, Page 22, Line 11–13
Children left alone	Caregiver 2, Page 14, Line 19–25, Page 16, Line 9–16
Interruption of studies	Caregiver 9, Page 5, Line 21
Siblings have to look after household work	Caregiver 12, Page 7, Line 23–26

(Contd...)

**Table 4:** (Continued).

Safety concerns	<p>Carer 4, Page 22, Line 6</p> <p>'Someone might just carry him away. These children are not aware of anything.'</p> <p>Caregiver 5, Page 16, Line 27–29, Page 17, Line 3, 4</p> <p>'When the children went to a special school on the bus, two other mentally retarded girls were also there with my daughter. The parents accompanied the children for a month each, in rotation. One cannot trust others. There is no safety for such children. Their teacher had said she could not allow any guard other than parents to accompany them. The vehicle should not have curtains or dark windows. It was 40 kilometres one way from the campus to the city. If someone stops the vehicle, they cannot even complain.'</p>
Social isolation	<p>Caregiver 6, Page 19, Line 3, 4</p> <p>'If I fall sick for even one day, no one can take care of her because she is a girl, no-one else can bathe or dress her. No one can be trusted'</p> <p>Caregiver 4, Page 13, Line 12–19</p> <p>'First, I gave up my job. Now, I cannot leave him alone and go to meet friends or relatives. I feel very bad...just because my child has some problem...slowly, slowly one gets cut off from society and friends'</p>
Psychological issues-	<p>Carer 4, Page 30, Line 26</p> <p>'I worry a lot. After me, who will care for him? Earlier, I was not scared of dying but now I am. If something happens to me, who will look after my child?'</p>
Worry for the children's future	<p>Caregiver 5, Page 18, Line 21–24</p> <p>'The problems are increasing as she is growing older. You know, she is a girl. Tomorrow, who can we leave her with? Is anyone worth trusting? If something happens to us, who will take care of her? My wife often sits and cries. I cry too at times.'</p>
Guilt, helplessness, anger, grief, frustration	<p>Caregiver 9, Page 7 Line 26–28</p> <p>'I also think that had I stayed with them at the right time, it might have been of some use. I kept trying to post on compassionate grounds for almost 13 years and finally when I did get a family station and the day I joined here on transfer, the same day she expired.'</p> <p>Caregiver 12, Page 5, Line 9–11</p> <p>'It can be very difficult. In case of any emergency, we cannot be there in time. Civilians, being locals, can take care of everything. They can look after anything requiring attention then and there. We cannot do it because of the nature of our duties. What can one do?'</p>

(Contd...)

**Table 4:** (Continued).

Spiritual distress	Caregiver 5, Page 25, Line 3–11  'I feel very angry with God. At times I abuse Him too. We have stopped praying. How much can one pray? We tried everything- worshipped, appeased, then grew tired and stopped everything.'  Carer 4, Page 19, L 25–27  'Some people say – 'This is the result of the parent's karma. These words cause such anguish. Who has seen anyone's karma?'
Information needs	Caregiver 4, Page 4, Line 7–13 'He was admitted to the neonatal intensive care unit. We had doubts – God knows what is the condition! They are hiding something! They had not told us he had CP and what were the future consequences. They only said that the child can have fits. We had to ask – 'What is the name for this condition? We searched on the net and read about it ourselves – searched on the net but no doctor told us anything.'  Caregiver 6, Page 11, Line 9–13  'The children asked but were too young to understand. God knows how they would react. I did not want their hearts to be burdened so I tried to manage everything on my own.'
Financial issues	Caregiver 4, Page 13, Line 21,22
Loss of employment,	'Earlier, I was teaching. After his birth, first I gave up my job.
Lack of reimbursement	Half of my husband's salary is spent on his treatment only. We are tired of borrowing again and again from our parents. Only a part of the expense is reimbursed, not all. There are many things that are not reimbursed – doctor's fees, investigations, therapies, transportation'
Support within the organisation:	Carer 4, Page 19, Line 22, 28–31  'I cannot imagine living alone outside the campus. I learned driving (smiling) – the unit people helped. My husband's colleagues taught me how to drive. Now I can take him for his daily physiotherapy on my own. God bless them for that.'
Practical, financial, and emotional support.	'In the civil people will try their best to just dig out your story. Nobody is actually interested in the problems. Over here, no one indulges in this kind of inquiry. People are more sensible.'
Sensitivity, respect for privacy Safety on the campus	'If for some time, I'm unable to look after him, or there is no one at home and I have to go to the hospital, I tell the neighbour. She comes and looks after him. In the civil, if you ask someone, they will make excuses. If your child needs emergency facilities, they are available 24 hours inside the campus. In civil, you will have to go far away. You can call over the phone and get help at home.'
Medical support.	
Attendant provided by the unit to help admitted patients.	Caregiver 5, Page 5, Line 14–22
Moral support	'I was in Manipur for election duty. The baby fell sick. The adjutant sahib said – 'Do not worry. I'm here to take care. He did not let my wife spend anything – even for food, sent one person, sent a vehicle. One person stayed in the hospital and one would bring food, medicines, etc., When I got my pay, I took Rs 2,500/- to pay him back in instalments. He refused to take it, saying – 'Had it been my child, would I not have done all this?'

BSF campuses feel adequately supported as they are a small, closely-knit community, looking after each other in their hour of need. There is a hospital, emergency care, and ambulance available 24 h. Most of the caregivers found other service families sensitive, helpful, respectful of privacy, and more supportive than civilian neighbours. Within the campus, the children are generally safe and secure, even if left alone.

## DISCUSSION

This study is in consonance with earlier quantitative and qualitative studies as well as systematic reviews about caregivers of paediatric palliative patients which highlight the substantial and heterogeneous support needs of caregivers of children in palliative care.<sup>[7-11]</sup> There is also evidence that service families face higher levels of stress, children's psychological issues, financial burden and delays and interruption in patient care – all compounded by having a family member with palliative needs and young children to manage, in the absence of the serving personnel.<sup>[2,12-14]</sup>

An expert consensus panel has recommended six domains for quality improvement in paediatric palliative care – continuity of care being one.<sup>[15]</sup> Learning of the child's diagnosis is highly distressing for parents and marked with emotional chaos. Communication, continuity of care, and symptom management in children are all found to be associated with long-term parental grief levels.<sup>[16]</sup> Retrospective qualitative studies have found that parents perceive continuity in relationships as the key to ensuring that clinicians know and care about the child and parents. 'Continuity also provides comfort and coherence in hospital environments, frees parents to sustain normal routines; enables parents and teams to share expertise, information, and goals, and improves the chances of timely recognition of changes in the child's condition'. All of this increases parents' confidence that their child will be given the best possible care.<sup>[15]</sup> The absence of continuous, caring relationships results in parents feeling frustration, hypervigilance, and mistrust of the quality of care. Healthy therapeutic relationships are vital to remind parents that they are not alone in their struggles. Communication and continuity of care are therefore valued by parents and considered vital for all healthcare staff.<sup>[17]</sup>

The interviews showed that lack of sufficient accommodation in family locations, frequent movements, and difficulty in getting leave make treatment and follow-up difficult. The social support system that may have been built up at one location is interrupted with each transfer and has to be built up all over again.<sup>[18]</sup> The personnel report difficulty in socialising with friends and family, hence the inability to develop the social support systems and safety network available to those staying in one place.<sup>[12-14]</sup> A government policy that allows 'exemption of government servants

caring for disabled children from routine rotational transfer subject to administrative constraints', is liable to subjective interpretation and cannot be implemented in armed forces due to the nature of duties.<sup>[18]</sup>

Psychological issues in serving personnel include guilt, helplessness, and anger at not being there for the family. The leave they are allowed is not sufficient to meet the needs of palliative patients.<sup>[12,14,18]</sup> Sometimes, they may not be able to attend even the last rites of family members. The wives feel overburdened, lonely, and resentful. Anxiety and worry affect both. This is also highlighted by a study of stressful life events in serving personnel which showed that out of 52, nearly two-thirds relate to leave, relocations, and family problems.<sup>[19]</sup>

A landmark study of 792 military children mentions that – 'probably the most severe stress a military family faces is enforced separation from the father. Whatever support he has been to the family is gone or reduced. In his absence, one member may take over the functions the father had, and family dynamics change. The wives left alone must learn to manage on their own. The family's expectations of him may differ from his own – resulting in rejection, anger, and frustration on both sides.'<sup>[2]</sup> Mental health issues, including anxiety and depression, were found to be more common in service families than in civilians.<sup>[2,12,13,19,20]</sup>

These issues have also been highlighted by Verma *et al.* for Indian paramilitary and Prakash *et al.* for army families.<sup>[12,13,18]</sup> Lagrone found that due to frequent movements, there is insufficient time for relations to develop with the local community. Relationships external to the family remain shallow. Force personnel may be seen by the local community as 'outsiders and transients' and viewed with mistrust and hostility.<sup>[2]</sup> All these lead to poor rapport with local healthcare workers, support from the community and repeatedly disrupted care.<sup>[2]</sup>

A Canadian report on Medicare in armed forces emphasises the 'stop-start nature of access to medical care in military communities, half of which are located in rural, isolated, or semi-isolated areas where care can be hours away, if available at all. Navigating new healthcare systems can be onerous and frustrating, with eligibility and reimbursement policies causing considerable stress.'<sup>[20]</sup>

Medical records of service families are sometimes not transferred efficiently from location to location. Providers can encourage them to keep copies of their medical records and help them locate services in their new location. Electronic records can be helpful but may not be feasible in remote areas.<sup>[20]</sup> Language can be another major barrier when living in non-native states. Complex communications may be facilitated by taking assistance from family members, staff, or unit personnel who can help with translation. 'Face-Rare' is a pilot intervention found helpful in eliciting and addressing the palliative care needs of children and using telemedicine to plan ahead and support families.<sup>[21]</sup>

Finances are reported to be a major challenge. Even though dependents get free treatment in BSF and state government hospitals; not all the services, medicines, devices, mobility aids, and equipment needed are available and have to be purchased out-of-pocket. Reimbursement is subject to limits. Other studies report similar regulatory barriers with a lack of reimbursement for many services needed to ensure a child's best quality of life and uncontrolled patient symptoms and financial difficulty leading to higher severe parental psychological distress.<sup>[18,22]</sup>

Spiritual distress was common and all psychosocial issues were more pronounced in the parents of paediatric patients in agreement with other studies on this population.<sup>[8,23,24]</sup> The notion of fate and 'Karma' are mentioned often. This concept helped most caregivers find acceptance and make sense of their circumstances, similar to the findings of earlier authors.<sup>[25-27]</sup> One mother, however, found the idea of her child suffering as a result of her karma very distressing. Counselling and support services for these carers are non-existent and need developing Gielen's study which found that more than half the subjects would benefit from spiritual counselling also recommends setting up these services.<sup>[28]</sup>

However, not all is bleak in service life. The people in the unit fulfil the role of 'next of kin' in the absence of family members. The caregivers report that service families support each other practically by looking after the children in the absence of parents, dropping siblings at school, helping with cooking and shopping, blood donation, bank work, official correspondence, financial help, guidance for obtaining welfare benefits, and legal and financial settlements. Emotional help is provided through moral support, encouragement, grief, and bereavement support. These are also built into the administrative duties of the armed forces.<sup>[18]</sup>

### Strengths

This article helps promote the awareness of the unique experiences of service families with children having palliative care needs. Education of the palliative care community in this regard can improve the quality and continuity of care and help deliver services tailored to their unique requirements. The study sample represents different geographical and population groups across India. The issues highlighted are common to rural Indians in general and the armed forces in particular.

### Limitations

The sample was taken only from service families so it may not fully represent other population groups with different experiences, facing different issues.

### Future research

Future research would be pertinent to the issues highlighted here, including the assessment of palliative needs in the

armed forces, the effect of educational programmes and interventions, and caregivers' suggestions for improving palliative service delivery in the armed forces.

## CONCLUSION

Issues related to children in families of patients with palliative needs are complex and involve many challenges – more so for service families. Frequent movement and social isolation disrupt medical care as well as family and community support systems. These along with the lack of access to paediatric palliative services in far-flung areas; guilt, anger, and helplessness in the serving personnel who cannot be present for their families due to the nature of duties; the wives having to manage alone in the father's prolonged absence, safety concerns for children when living outside the campuses; financial burden due to restrictive reimbursement policies, language, and cultural barriers when living in distant parts of the country-lead to distinctive issues in this population. However, the medical and administrative support from the organisation and other families within the campus provides a safety net. Awareness and education of the palliative service providers about the needs of children from armed forces families can help provide better care and support to patients as well as caregivers.

### Ethical approval

The author(s) declare that they have taken the ethical approval from IRB/IEC.

### Declaration of patient consent

Patient's consent was not required as patients identity is not disclosed or compromised.

### Financial support and sponsorship

This study was done as the dissertation for MSc (Palliative Medicine), Cardiff University, UK; for which the first author received a Commonwealth distance learning scholarship.

### Conflicts of interest

There are no conflicts of interest.

### Use of artificial intelligence (AI)-assisted technology for manuscript preparation

The authors confirm that there was no use of artificial intelligence (AI)-assisted technology for assisting in the writing or editing of the manuscript and no images were manipulated using AI.

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**How to cite this article:** Butola S, Butola D. Issues Related to Children-Faced by Armed Forces Families When Caring for Patients in Palliative Care – A Qualitative Study. *Indian J Palliat Care* 2023;29:437-46.