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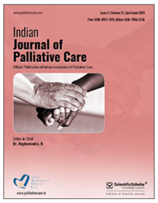

Original Article

Caring and Conflict-Palliative Care in the Armed Forces: The Challenges for Caregivers

Savita Butola[1], Sushma Bhatnagar[2], Fiona Rawlinson[3]

[1]Border Security Force, Gwalior, Madhya Pradesh, [2]Department of Oncoanaesthesia and Palliative Medicine, Dr. B.R.A IRCH, All India Institute of Medical Sciences, New Delhi, India, [3]Centre for Medical Education, Cardiff university, Wales, United kingdom.

ABSTRACT

Objectives: In India, Palliative care remains inaccessible, especially in remote areas. This study aimed at exploring the experience of caregivers related to arranging palliative care at home, for personnel and family members of an armed force.

Materials and Methods: Qualitative study based on thematic analysis of semi-structured interviews with adult caregivers - either serving personnel or their dependent family members.

Results: Lack of palliative care in rural areas makes arranging home care challenging for Indian caregivers, especially in armed forces. The families stay alone and personnel cannot be there to look after loved ones. Constraints of leave, financial and legal problems, frequent movement and social isolation disrupt care as well as family and community support systems, leading to psycho-social problems and stress for the serving personnel as well as families. Educating staff, integrating palliative care into existing medical services, coordinating with other agencies to increase awareness and provide care at home, access to opioids, timely leave, reimbursement of expenses, increased family accommodation, guidance about benefits, and considerate implementation of transfer policy can help mitigate some of their problems.

Conclusion: These caregivers face physical exhaustion, psycho-social, financial, legal, and spiritual issues- some common to all rural Indians and others unique to the armed forces. Understanding their experiences will help the providers find solutions, especially in relation to the unique needs of the men in uniform.

Keywords: Armed force, Border Security Force, Caregiver, Pain, Palliative

INTRODUCTION

"Caring and Conflict - Palliative Care in the Armed Forces: The Challenges for Caregivers"

"In uniform, he is tied up at three levels - at the bottom with his shoes, in the middle with his belt, at the top with his cap. What can he do? That is the whole matter!"

- Constable caring for teenaged daughter with chronic neurological disorder and mental retardation

Palliative medicine aims to improve the quality of life, not only for the patient but the family too.[1] Caregivers, 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.[2] Caring is largely hidden work, often taken for granted, yet crucially important for people to receive optimal care and achieve a good death.[3,4] It has been found that illness in one family member profoundly affects the psychological and physical health of the caregivers-termed "hidden patients" because their requirements remain unnoticed.[5] Caregivers are therefore the center of interest all over the world.

Aim

This study was aimed at exploring the experience of caregivers related to arranging palliative care at home for members of an armed force and their families.

India has little qualitative research about caregivers in palliative care.[6-9] A literature search yielded only four articles about palliative care in the Indian armed forces.[10-13] Three[10-12] were expert opinions about the need for "End of life" and palliative services in the forces. The fourth - about "Knowledge, attitude,

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*Corresponding author: Savita Butola, Chief Medical Officer (SG), Border Security Force, Gwalior, Madhya Pradesh, India. savitabutola@yahoo.com

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and practices regarding palliative care" among Border Security Force (BSF) doctors, showed that 75.5% were unaware of the basic concepts.[13] There was no study about caregivers for this population. This unexplored topic was therefore taken up to research their experience as compared to that of civilians, with the aim of creating awareness and facilitating a change in practice and policies so that palliative care becomes available for the Indian armed forces in future.

The BSF is an International, border guarding armed force of the Union of India.[14] Besides securing the borders, it performs other important duties such as internal security, counter-insurgency and disaster management. Life in armed forces is stressful and demanding.[15] Although personnel are recruited from all over India, the majority belong to rural areas[16] where infrastructure and health-care facilities are limited. Their workplace is an outpost at the international border; in conflict ridden or disaster affected zones, due to security reasons, these are out of bounds for family members to visit or stay. The men live apart from their families throughout their service years - except during 2 months' annual leave and 15 days' casual leave. Permission to stay with families in campuses (administrative bases with some family quarters), is granted in rotation to a fixed percentage of personnel. Some may not get the chance throughout their service. The wives bear all the family responsibilities alone.[17] The changing social fabric has seen more nuclear families living in towns, away from the security of the traditional joint families in villages where a mixture of old and young members looked after each other.[18,19] The family might be staying in a city for the children's education. The old parents are left alone in the village while the earning member is thousands of kilometers away in another part of the country. If any of them becomes ill and needs care - it is a very fragmented family that has to manage - with all the superimposed disadvantages that India faces in terms of healthcare and infrastructure. Some of the issues they face are common to all Indians, while others are unique to uniformed forces because of the nature of the organization and the duties they perform. Studying the caregivers' experience in this situation would therefore help understand how to support them better.

MATERIALS AND METHODS

A qualitative methodology using "thematic analysis of interviews" ("Grounded theory") was chosen because "standard quantitative techniques, dependent upon statistical procedures of quantification, are inadequate to fully explore the richness of human experience," "seek meaning and understand processes and phenomenon."[20]

The participants were caregivers, looking after patients receiving palliative homecare within the last 3 years. These patients were either serving BSF personnel or their dependent family members.[21] [Table 1] lists inclusion and exclusion criteria.

An interview methodology was used to explore the topic. In focus groups, people may find it difficult to express their innermost feelings in front of others.[22,23] An in-depth study with fewer careers might have been too limited for the study's broader aims. Semi-structured interviews were considered more suitable as they could highlight better the issues facing various groups-serving personnel, family members, older adults or children; revealing rich data and a large amount of information through open ended questions, which need not follow any specific order and may develop between interviews - each interview being informed by the previous one.[22,24] Ethical approval was obtained (Institutional ethics committee-Letter number-PA/CH-Jal-IEC/2016/355-356/ dated 15-3-2016). The eligible beneficiaries were listed, randomly selected and invited to participate via letter. Acceptance rates are shown in [Table 2]. Subjects were provided information sheets in Hindi and English. They could refuse participation anytime without negative outcomes - especially important as they are "vulnerable research subjects" (incapable of protecting their own interests because of disability, lack of

Table 1: Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria

Adult careers (aged more than 18 years) of patients with the following conditions:
Careers - defined as '*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.*'[2]
Palliative care and caregiving by family/ care by the personnel from the unit are considered as starting from the time of diagnosis.
• Cancer
• HIV/AIDS
• COPD
• Chronic renal failure
• Chronic liver failure
• Paraplegia after Spinal Cord injury
• Paraplegia or hemiplegia after Cerebro-vascular accident
• Children with Congenital malformations
• Cerebral palsy
	Those who were:
	• Not willing to participate
	• Lacking capacity
	• Not able to communicate effectively due to:
	  • Disability
	  • Lack of common language for communication

• Either serving personnel or their dependent family members • Registered within the last 3 years	• Those whose relative died within the last 1 year

power, communication ability or diminished autonomy due to dependency or being under a hierarchical system, e.g, terminal patients and defense services.)[25] Serving personnel with palliative needs are therefore vulnerable on two counts. Those refusing participation would be replaced by another from the possible participants.

Informed, voluntary, written consent was obtained in consent forms adhering to ethical guidelines. After deciding the date, time and language of the subjects' choice through phone or email, interviews were conducted between April and July 2016 at their residences, ensuring their preference and comfort.

The interview guide was informed by the literature search and piloted. Field notes were made. Interviews lasted between 45 min and 4 h 20 min (average-90 min), conducted either as a whole or over more than one sitting, were recorded in a digital recorder. The average was three sittings per person. Two interviews required only one sitting. In two interviews, the patients' fathers were accompanied by the mothers. In another, a husband and wife - both patients - were present together. Initially, enquiring general details, facilitated introduction and rapport formation. Subjects were allowed to narrate their caregiving experience uninterrupted; questions being asked only as per the pre-decided format [Table 3]. A "distress protocol" was established to support distressed subjects.[26] The investigator could terminate the subjects' participation without their consent if they became physically or mentally incapacitated or too distressed during research.

Anonymized data were stored confidentially on a hard drive. The study, an MSc dissertation, had a time limit, so ten-twelve interviews were considered optimum.[27] After twelve interviews, new themes were still emerging. Data saturation occurred after fifteen interviews. Data translated from Hindi to English, were transcribed verbatim by the investigator for exact transcription and documentation of finer nuances and non-verbal communication.[28] A school teacher proficient in both languages randomly checked translation.

For analysis, each transcript was read numerous times. The important comments, thoughts and reflections, highlighted and noted in the margins, formed descriptive codes. Themes were found by color-coding, listing chronologically, grouping codes into categories, and identifying common points between themes to find super-ordinate themes. The investigator and research guide perused them twice more to ensure complete representation of interviews, agreed on findings, and finally listed the major themes.[29]

The researcher and her husband, both third generation of serving families, have served in BSF for 24 years. The researcher had cared for family with palliative needs years before training in palliative medicine. This adds depth to the understanding of issues concerning this population but is also bound to introduce preconceptions which were avoided as follows:

Selection bias and channeling bias, likely when medical personnel perform patient assignment, were avoided by randomization through drawing lots to establish the sample. Recall bias was avoided by recording the data accurately. Interviewer bias was the most significant here. The effect of the interviewer's own rank on the participants could not have been entirely eliminated but effort was made to minimize it by interviewing subjects in their own homes, in civil dress to maximize their comfort. Being an "insider," the researcher had not only witnessed the involved issues as a doctor but also experienced them as a caregiver. However, this lent additional insight into responses, enabling further exploration of themes during interviews.[30,31] After completing analysis, member checking was done by three subjects for internal validity.[26]

Table 2: Acceptance rate for interview.

Letters sent two invite participation	50
Agreed	21
Subsequently unable to participate due to:	
Transfer to a different location	2
Temporary duty	3
Did not want to revisit grief	1
Total	6
Total interviews	15

Table 3: Questions for semi-structured interview.

Name
Age
Sex
Educational Qualification
Occupation
Contact details- Address, Telephone number, Email address
Name , Service number, Unit of serving personnel
Relationship with patient
Diagnosis
Year of diagnosis
Year of death
Awareness of diagnosis and prognosis-and its effect upon the patient and family
Was the treatment/ place of care/place of death discussed with the patient and family?
What were their needs for information and to what extent were they met?
What was the experience of caring for the patient at home like?
What were the financial, psychosocial and spiritual issues?
What was the support they got and who provided it?
Did the organization support their needs? If yes how?
What grief and bereavement support did they receive?
What suggestions would they give for the care of similar patients?
Is there anything else they think important and would like to share

RESULTS

Demographic characteristics

All the participants were young, married, and predominantly rural. 12 participants were serving (3 officers, 1 SO, 8 ORs), three were wives. Four cared for more than one patient simultaneously [Table 4].

Major themes after analysis

1. Lack of accessible healthcare [Table 5]
2. Lack of palliative care [Table 6]
3. Issues faced by caregivers [Table 7]
4. Strengths and limitations of armed forces [Table 8]
5. Gender issues [Table 9]
6. Caregivers' suggestions [Table 10].

Lack of accessible healthcare

BSF hospitals provide free Medicare [Table 5] but are limited to few locations. Like other rural Indians, service families in villages lack accessible healthcare, mainly due to illiteracy, poverty; long distances, travel time, lengthy waiting periods; poor communication, lack of transport, and inadequate arrangements for caregivers' stay in hospitals.

Lack of palliative care

Beneficiaries' and providers' ignorance [Table 6]; paternalistic medical practice; belief in traditional remedies, quacks and traditional healers; lack of opioids, participative decision-making and advance care planning appear to have contributed to poor symptom control and place of care decisions, especially at end of life. Only four patients received early referral through BSF hospitals. None treated initially in medical college hospitals received palliative care there. All caregivers reported severe, unrelieved symptoms, including pain. Five patients reportedly requested euthanasia. All, including two who were doctors, had unmet information needs regarding diagnosis, prognosis, illness trajectory, treatment options, availability of therapy/equipment, diet, expenditure, and home nursing.

Table 4: Demographic characteristics.

Total	15
Age	
Less than 45 years	15
Marital status	
Currently Married	12
Widowed	2
Divorced	1
Other family members also serving in armed forces	7
Sex	
Males	5
Females	10
Rank wise distribution of serving personnel whose dependent needed palliative care	
Officer	4
Subordinate officer	1
Other Ranks	10
Interviewed subjects - whether in service or family members	
Serving personnel	13
Family members	2
Relationship with patient	
Colleague from battalion	1
Caring for spouse or parent	9
Caring for child	5

Collusion was common, with caregivers requesting staff to withhold information, evading or lying outright when patients ask questions - preventing open discussion and planning. Ten caregivers were unprepared for patients' death. Lack of information and social pressure to "do the best," kept families searching for cure; resulting in futile, expensive treatment, worsened by profit oriented, inappropriately curative practices in the private sector.

Issues faced by caregivers

Fourteen subjects reported exhaustion [Table 7], lack of rest and sleep. Twelve mentioned financial problems. Multiple private consultations caused substantial personal expenditure. Personal preference for treatment was limited since expenses are reimbursed for government hospitals only. Some equipment, supplements and therapies, even though essential, are not reimbursable; others are subject to rate limits. Seven caregivers were unaware of referral or reimbursement procedures. Lengthy procedures discouraged four from filing reimbursement claim.

Everyone reported emotional issues - sadness, anger, guilt, resentment, regret, grief, and worry about leave; the family's future and patient-care. Five caregivers were distressed by the lack of empathy and gentleness with patients; and concerns not being heard by health-workers. Spiritual distress, reported by nine subjects, appeared greatest in parents of pediatric patients. An officer's wife was traumatized by the thought of her "karma" being responsible for her child's illness. Six subjects felt sustained by their faith.

Fourteen subjects had young children (aged 4 months to 14 years). Their care, disturbance of studies and safety were chief concerns. Social isolation due to limited mobility, lack of disabled access and social stigma, worsened by illiteracy and myths, made caregivers feel lonely.

Organizational strengths and weaknesses

BSF serves in remote, inhospitable terrain [Table 8]; connectivity is poor and personnel often remain cut off from families. Communication and travel are difficult

Table 5: Lack of accessible healthcare.

Sub-themes	Quotes from interviews
Distance to nearest Health Care Centre	Caregiver 2, Pg 19 Line 2-12 (Widow serving as a constable, caring for mother with breast cancer) *“One has to change three buses to reach the hospital. The nearest (bus-stop) is a kilometer away. We walk till there, 7 kilometres for the second bus, another 5 kilometres for the third one, then take an auto-rickshaw for the hospital.”* *Interviewer: ‘How long does it take?’* *Caregiver 2: “About two hours if you get all connecting buses in time. If not, then three hours. And if they're delayed by half an hour, add that. She's old and can't manage by herself. Once we sent her alone and guided her over the phone but she kept saying, ‘I feel there's something wrong’ She had travelled in the wrong bus, travelling in the opposite direction. After a few hours, we found her back in the village.”*
Unqualified practitioners - the first line of healthcare provision Delay in diagnosis Use of herbal/ home remedies delaying treatment	Caregiver 15, Pg 1 L4-7 (Constable caring for father with cancer oesophagus): *Father told me- “When I try to swallow anything, my throat hurts.' In the villages, they say it must be because of eating something hot or cold. He took traditional treatment in the village for almost 3 years before we found out what it was. Someone said, ‘Try this home remedy', others said- ‘Try that herb'. You know people in the villages have more faith on traditional medicine than hospitals*
Multiple consultations in private sector with out- of -pocket expenditure	Caregiver 15, Pg 3 L 12-24 *We went to every place, every doctor they suggested. Even to Haridwar for ayurvedic medicines but he kept getting weaker… the swelling in the neck, over 2-3 years…it kept increasing. He spent a great deal of money but to no avail.”*
Lack of arrangement for caregivers to stay in hospitals	Caregiver 2, Pg 15, L 12-17, 22-28 (Widow of a constable who died of AIDS): *‘He slept on the bed. I slept on the floor nearby. There was no facility for food. If you need juice, get it from the shop. If the patient wants to eat something- even as he is breathing his last, if he has the desire to eat something, he can't get it. There was no facility to cook separately for the patient. One had to buy everything from the market – whether unhygienic or adulterated. We ate that food for three months! There were three other patients in that room. I had to sleep there in front of those men. For a lady, it‘s so difficult. I slept on the floor for three months. There were such huge mosquitoes too. Sometimes, I couldn't sleep a wink”* Interviewer: *‘There was no place to sleep?'* Caregiver 2- *“No! Nowhere to eat, cook, sleep or wash clothes. I had to wait the whole day for an opportunity to bathe. If there was someone in the bathroom- I had to go and come back again - maybe five times in a day, waiting for it to be vacant. If it was occupied, I had to go back. Sometimes, it would be evening before I could have a bath.”*

during emergencies. Frequent transfers every 2–3 years disrupt life. Developing and maintaining support-systems is difficult. The place of posting is undisclosed till the last moment, preventing future planning and increasing stress. Land and property disputes due to incomplete service records or financial nominations are other important concerns.

Family locations as well as accommodation are limited. Wives are left alone- simultaneously looking after patients, running households and bringing up children. In the husband's absence, socializing is curtailed. Role reversal and change in expectations affects family dynamics- “the military family syndrome.” Families staying inside BSF campuses got organizational support but those living in other cities got neither the security of campuses nor the support of extended village clans. For soldiers, it caused worry, helplessness, guilt and anger at the organization whereas family members felt abandoned, fatigued, anxious and depressed.

Getting leave from duty - a universal concern

Operational commitments and inherent nature of duties prevents soldiers from getting leave whenever required or for long periods. India being vast- much of the leave is spent in travel. Two months' leave a year is anyway too short to manage patient-care. Getting leave determined the soldiers' perception of official systems - helpful or frustrating - even as they acknowledged that getting leave whenever needed is not always feasible.

Soldierly attitude

Force personnel are trained to tolerate discomfort and pain; be independent, self-sufficient and value physical ability above all else. As patients, they find giving up control and accepting help- even from spouses - difficult. This interfered with symptom reporting, assessment, treatment, and predisposed to depression.

Table 6: Lack of access to palliative care.

Sub-theme	Quotes from interviews
Lack of awareness Late referral to palliative care Inadequate symptom control	Caregiver 5, Pg 8, L 5-11 (Constable, cared for wife, bed-ridden with rheumatoid arthritis, multiple joint contractures and ischemic gangrene of feet): *"For eighteen years, I literally carried her everywhere. Carried her here and there and tried my best to take care of her. To the best of my ability and even more than that. By the time we got palliative care and morphine was available, it was too late. It came in only at the end. Had it been there earlier…a few years at least, could have passed in comfort. She suffered all these years."*
Inadequate pain management	Caregiver 8, Pg 7 L 3 – 7 (Officer, cared for 81years old father with cancer) *"He was not able to sleep. After one or two hours - he'd go- "Aaaah, aaaah, this is killing me!" the whole night, he would be crying. Once he was under the influence of medicines, he would be alright for a little while, then he would be crying again. In the middle of the night he'd be crying - "It's killing me, it's killing me"* Caregiver 15, pg 3 L 5-8 (Head-constable, cared for father with esophageal cancer): *"The pain kept on increasing and increasing. My mother would sit with him the whole day and throughout the night. Sometimes he'd say-—'Massage my head', at others, 'Press my legs'. She'd always be doing something to make him comfortable. He'd say— 'Apply mustard oil. Apply butter'. He'd sometimes tell her, 'Take a knife and cut it out. This lump here- cut it out with a knife.' With medicines, the pain would be relieved only for half an hour or one hour, otherwise it was continuous. He had terrible pain- couldn't sleep the whole night… and the whole household would be up. None of us could sleep when he was crying in pain.' (Voice choked with tears) Whoever was with him was also disturbed but he couldn't be blamed- pain is such a terrible thing!"*
Procedural pain	Caregiver 4, Pg 27 L 17-20 (mother of a 5 years old with cerebral palsy and refractory epilepsy): *"It's so difficult to take a blood sample from him. Not everyone can take it. They have to put in the needle repeatedly. When it has to be drawn, I start feeling scared. Oh God! If it's drawn in the first attempt only, it's better! Sometimes he has to be pricked 5-6 times. It hurts so much to see him in pain...he sobs so much. I can't bear to even look at him.'*
Unmet information needs Effect of communication on informed consent Lack of co-ordinated care	Caregiver 4, Pg 4, L5-12 (mother of child with cerebral palsy): *"The baby had not cried for almost ten minutes after birth. They said that as he was born premature and I had hypertension during pregnancy, he had to be observed in intensive care nursery. We kept asking- 'Is he alright?' But no-one told us the real problem. We, however, had doubts– 'God knows what's the condition! They're hiding something!' They hadn't told us he had birth anoxia and what were the future consequences. They only said that the child can have fits. We had to ask, "What's the name for this condition? Later on, they said it could be cerebral palsy. We searched on the net and read about it ourselves. What is it? How does it happen? How many cases are there, what are the implications? We searched on the net but no doctor had told us anything. Nobody asked or told anything. They just decided on their own."* *Pg 29, L 15-23* *'At that time, no-one gave us the option. Now they say, 'The child is suffering. It would've been better not to save him at birth'. Many doctors said that this child shouldn't have been saved. No one asked us when he was put on ventilator. At that time, we didn't know what would be the consequences. They only asked – 'He's not breathing regularly- 'Is he to be put on ventilator or not?' Had they explained things, discussed the pros and cons, then maybe at that time, we'd have...maybe we'd have decided differently...Looking at the condition of these children later in life, one feels it would have been better, had we not saved him!"* Caregiver 15, Pg 12 L 23-29 (Constable- cared for father with esophageal cancer *"We kept running from one place to another, One hospital to another, one department to another. No-one told us where to go, what to do. Then the doctor said- 'We have to take a biopsy.' They called us in and gave us a form to sign. I signed it and gave it back. No- one explained what it (the form) was for but I had noticed that when they take the patient into the operation room- they get it signed… so I assumed it's the form signed by patients going for surgery. Then they took father inside. I kept sitting outside.'*

Table 7: Issues faced by Caregivers.

Sub-themes	**Quotes from interviews**
Physical issues Exhaustion Fatigue Lack of rest and sleep Family issues Multiple family members needing palliative care Need for more than one carer	Caregiver 3, Pg 13 L 13-34 (Medical professional, cared for father with Parkinson's disease. His mother was the main caregiver): 'She was an old lady. it was not possible for her to do things like she did earlier. During the earlier years of illness when sometimes he would say, help me get up, my mother, being by his side, would help him up but now, all her joints start creaking. He was quite heavy- weighing almost 75- 80 kg. For an old lady to pick him up, was difficult. She had herself been operated for a disc problem and undergone various other surgeries. She would be up the whole night. He, poor man, would keep on with- 'Help me up, turn my side, help me lie down, do this, do that.' Then during the day, he would keep dozing while she had the whole house to manage. It left her totally exhausted. I was scared lest my mother should also fall sick. If she too would have been on the bed, then it would have been double the problem. We had to arrange 3-4 boys who could help him, but not everyone can afford that."
Psychological issues- guilt, anger, worry, helplessness, grief	Caregiver 9, Pg 6 L 24-28 (Constable looking after bed-ridden wife with Rheumatoid arthritis) *"The worries of life are such! It's very painful, especially for a member of the force. If the posting isn't there at the right place, at the right time, then…I often think that had I been able to stay with them at the right time, it might have been of some use. I could be with her for only ten days in all. The day I joined here on transfer, she expired."* Caregiver 4, Pg 12 L 28-36 (Mother of a 4 years -old with Cerebral Palsy): *"Some people say –'This is the result of the parent's karma.' I've heard this innumerable times. Almost fifty percent people tell me - 'It's the result of one's own karma. It's one's own karma that one has to bear. Some karmas of the child - some karmas of the parents. These words cause such anguish… Then one feels it's better not to meet anybody. Such nonsense! Parents are obviously hurt by such words.* Pg 19 L 25-27 *Sometimes I feel like asking that person- "Which karma? Who has seen anyone's karma? It's not necessarily my karma alone. In the whole family, is it only my karma that affects the child's life?"(In tears…long pause)'*
Legal issues	Caregiver 8, Pg 23 L5-10 (Officer, caring for father with prostate cancer) "If the person is not able to settle his legal and financial matters while in service, it can lead to a lot of problems. Sometimes the wives' or parents' names are not entered into the service record or provident fund and pension nominations. Often a young bride is turned out by her in-laws to avoid giving a share in the property. Sometimes, the wife walks away with everything- leaving the old, poor parents without anything"
Land and property concerns	Caregiver 13, Pg 5 L 26-29 (Officer caring for bed ridden hemiplegic mother with aphasia and father with cardiac failure) *"Another issue is the care of our ancestral house while my parents are sick. Mother is bed- ridden with stroke and father has a heart problem. They stay with me but our parental house in the village is lying locked up. My father has spent his life's savings- the entire money earned during service- on its construction and today it is just lying there vacant...locked up! Going there frequently to check on it is also not easy for me."*
Financial issues Loss of employment Substantial "out of pocket expenditure"	Caregiver 6, Pg 6 L 3 -12 (Widow of a constable who died of cancer): *"He had to have surgery for the cancer in his mouth. On the day of the operation, we spent almost Rs 100,000. Some of it, the relatives gave. I mortgaged some jewellery. They asked us to deposit 25,000/- for radiation. As soon as his salary would come, we'd deposit it. Household expenses were borne by my family. There was no money for even food and water"*
Social and family pressure to "do the best possible" Inappropriate, futile curative treatment	Caregiver 3, Pg 15 L 5-14 (Medical professional, cared for father Parkinson's disease with cerebro-vascular accident) *"Mother kept insisting- 'Take him to a bigger hospital.' We knew what is going to happen, what kind of systems even good hospitals have. We were aware that he'd be much more comfortable at home. Father was also unwilling – he had told us earlier that he wanted to be at home at the end, but had we not taken him- within the social circle- people would have sniggered, 'These people deliberately avoided taking him to a better hospital. They have inherited all the property but they never took him to a bigger institution to avoid spending on him."*

(Contd...)

Table 7: *(Continued)*

Sub-themes	Quotes from interviews
Lack of awareness about procedures for referral in the organization Lack of awareness about reimbursement procedures Lengthy procedures for filing reimbursement claims Children's issues including: Security Household work managed by children Adverse effect on studies Protection from abuse Worry for care after parents' death	Caregiver 15. Pg 4, L 26-29 (Serving constable caring for wife with refractory leukemia) *"All my brothers live in the village. They're all farmers. With both of us admitted in hospital, finances were a problem. At that time, I didn't know that I could claim the expenditure. They kept buying all the medicines. I didn't get any of that that money. The doctor and Officers told me later – —'How foolish you are! You should've kept the bills. You could have got all that money through reimbursement of bills.' My brothers didn't know. They are not very educated. None of us knew".* Caregiver 2, Pg 11 L 21-23. (Serving constable- a widow on compassionate appointment –cared for husband with AIDS): *"When my husband got tuberculosis, I had to take him to Delhi for treatment. The children had to be left behind in the village. They were alone…too young to do the cooking. I was very worried about them. I just left them at God's mercy. It was very difficult, of course, to leave them alone but I just put them in God's care'* Pg 14 L 22-26, *"The children would sometimes have a bath before school, sometimes not. Sometimes eat before school, sometimes not. Sometimes they boiled rice, sometimes they got something from the shop. After school, they'd wash their clothes in the machine. They were in a very poor condition.* Pg 16, L 26 *They couldn't study at all that year."* *Caregiver 5, Pg 18 L 21-25* *(Constable caring for teenaged daughter with Chronic neurological disease with mental retardation)* *"One can't trust others. There's no safety for such children. They can't even complain. My wife and I often sit and weep- when we think of who will look after her when we are gone!"*

BSF medical facilities

BSF medical facilities were reportedly supportive for ten subjects**,** three found them unhelpful; two patients were non-entitled. Some relatives though not authorized treatment[21] remain dependent for care - taking away the advantage of free Medicare while all disadvantages of force life remain. Family members felt out of place in campuses and wanted to return to their native places but insufficient housing in campuses and inaccessible healthcare in villages makes both staying and leaving difficult. Eleven caregivers received guidance; encouragement; help with finances, transportation, blood donation, shopping, cooking, and childcare from colleagues but none of this help can reach families in villages. Many requested for transfer near hometown, which was not always possible.

Attendants provided from the battalion

Colleagues, who care for sick personnel as family would, stay with them, provide companionship and link the hospital, battalion, and family are a unique support-system. Spiritual support and bereavement care through funeral assistance, children's education, and compassionate jobs for families is inbuilt in the forces.

Females were principal caregivers

Females were principal caregivers [Table 9] for ten patients. Three were pregnant; three were sexagenarians suffering from arthritis, diabetes, or hypertension. All reported exhaustion, anxiety, insomnia, depression, and isolation. Two widows, blamed for their husband's illness, were deprived of property rights. Healthcare staff usually conveyed information to male relatives, who took decisions without consulting the women.

Caregivers' suggestions

Caregivers' suggestions: [Table 10] included increasing palliative services; support groups, long-term care-homes, coordinating with non-government - organizations; improving transportation; and enhancing awareness of entitlements.

DISCUSSION

This research highlights issues reported about caregivers[2-5,32-38] by other authors but also reveals challenges distinctive to armed forces. Similar lack of accessible rural healthcare,[39-43] awareness, education, opioid availability and policy implementation as barriers to palliative care[44,45] and futile, inappropriate treatment being common in India have been published earlier.[46,47]

Financial hardships preventing normal functioning, causing worry, difficult coping, conflict, stress, decreasing expenditure on housing, others' education or health and ignorance of benefits and entitlements match those reported by caregivers around the world.[3,4,47-50] In India, 70-80%

Table 8: Limitations and strengths of the armed forces.

Sub-themes	Quotes from interviews
A stressful, unsettled life Frequent relocation	Caregiver 13, Pg 8 L 9-32 (Officer caring for mother with hemiplegia and father with cardiac failure): *"Both my parents are old and sick and stay with me. He's a retired army person and gets pension so he is not authorized treatment from BSF hospitals. The campuses are usually so far from the city that we cannot take them to the hospitals where they are authorized treatment. Or arrange any home nursing care for them. My mother had a stroke and became paralyzed when my wife was in early pregnancy. Ever since then, she has been taking care of them. I have two small children and my wife is managing everything on her own. She had to give up her teaching job. Now I'm due for transfer and again under stress that after six months, I'll get posted out. I don't even know where I'm going next year so I can't even plan anything. One is travel…I'll have to carry mother and father with me. There'll be the same problem again. We'll have to look for a physiotherapist, medical support and whether a quarter is available in the campus or not. I often think that leaving the force would be a better option if we can't even look after our loved ones when they are dying"*
Leave from duty	Caregiver 8, Pg 12 L 26-27 (Officer, cared for father with prostate cancer): *'Even if someone in the family is terminally ill or is dying- one knows he is dying but has to leave and go back to duty'* Pg 12 L 34-37 *"When father was terminal, I was in anti- naxalite area. My leave was over and I had to go back. Father was so angry he wouldn't answer the phone…wanted me to stay and look after him in his last days. How could I? It was not a matter of one or two days.' He again said – "Stay here. Look after me. You don't care for your old man."* Pg13, L 11-15 *'A person can get leave once, twice, maximum thrice. If only one person gets leave, what will the others do? From Chhattisgarh, going to Andhra, Garhwal or Punjab, all the money and half the leave is spent in travel."*
Remain cut off from family Social support systems difficult to develop and maintain	Caregiver 12, Pg 5 L9-11 (Head constable–caring for child with post-hydrocephalus mental retardation): *"It can be very difficult. In case of any emergency, we can't be there in time. Civilians, being locals, can take care of everything. They can look after anything requiring attention then and there. We can't do it because the nature of our duties is such.'* Caregiver 8, Pg 21, L14-15,26-27 (Officer, cared for father with prostate cancer): *"We attended a family wedding recently- the first time in 22 years, just imagine! Now when we remain cut off from family… can't go in their hour of need, they won't come for us.*
Transfer policy implementation issues	Caregiver 10, Pg 4, L6-8 (Wife of subordinate officer with paraplegia) *'My husband had applied for continuation in a particular location, since he is now paraplegic and on a wheelchair. However, we understand that due to policy constraints, it's not possible to always remain at one place. He had submitted an application for continuing his posting here, if it could be made permanent here but that is not possible. No-one has a solution to this- neither we have nor they have'*
Attitude of fighting till the end	Caregiver 5, Pg 2 L 7-13 (Officer caring for father, a retired para-trooper with Parkinson's disease) *Father would say, "Son, physical fitness was my pride. Once upon a time, if there was a ten-kilometre run, I'd be the first ones. This is the same man in front of you, who never thought twice while jumping from an airplane and today, to get up from this bed, he has to think four times."* Pg 3 L 12-14 *"On his last morning, he said- 'Get my beard trimmed'… then – 'Put my shoes on and take me for a walk'. This, when he had been on ventilator for ten days! And imagine, the same night, he passed away!"*
Support from other personnel and families within the organization	Caregiver 2 Pg 12 L 3-3x5, Pg 13 36-41 (Cared for husband dying of AIDS) *"My in-laws blamed me for my husband's infection and treated me as an outcaste.it was the colleagues' wife who supported me when my husband lay dying. She'd call me and ask, 'How are things, sister? How are you? Don't worry. Be brave.' Three-four times, she came to visit me in the hospital. She stayed with me. He had another friend in the Air force- his wife came to visit and stayed with me to help. She would cook his favorite dishes- whatever he would ask for- and bring it to the hospital. Whatever financial help was required, that too, these people gave. His family did nothing to help us."*

(Contd...)

Table 8: *(Continued)*

Sub-themes	Quotes from interviews
Facilities in the campus	Carer 4 Pg 9 L 18-20 (Mother caring for child with Cerebral palsy and refractory epilepsy) *“I learnt driving (smiling), that too, within the campus. My husband’s colleagues taught me’.* Pg 22, L 2-22 Interviewer: *How do you think the experiences of families in the forces differ from civilians?* Career 4 *‘First of all is the security. If you’re out for a walk or some work, you’re not worried that someone will kidnap your child. In the civil, someone might just carry him away. These children aren’t aware of anything. 24 hours’ medical and emergency services are there. They come home to take samples if he is not fit to be carried to hospital. My neighbors take care of the child if I am sick, sit with him. Help with cooking and shopping too.* *In the civil, there are so many things you’d get to hear. Wherever you go, even if you’re travelling, your co-passenger will ask- ‘Does this child have a problem? Why is it? How is it?’ You can’t share your story with everyone but people will try their best to dig it out. Nobody is actually interested in the child or the problems you’re facing; just the story is what they want. Over here, no-one indulges in this kind of enquiry. People are more sensible. They treat one more sensitively.”* Caregiver 14, Pg 7 L 24-30 (Constable caring for wife with refractory leukemia) *“There are people who have affection for each other and there are others who don’t care. In the force too, there are people who don’t have anything to do with the world. They are concerned only with their children, their family. They are fewer in number. If I fall down somewhere, the ones to pick me up are these personnel only! The ones who don’t care are fewer. The ones who do care are much more in number.’”*
Issues when parents/older family members of personnel stay in campus: Feel out of place Miss their own home, company and lifestyle	Caregiver 2, Pg 17 L 22-24, 29-32 (Constable caring for mother with breast cancer) *“She has cancer of the breast and I’m worried sick. I brought her with me. She stayed for a few days, but feels tied up here. She doesn’t want to stay here. Feels lonely. She’s never been away from her home in the village. My house is on the fourth floor. She can’t climb stairs. She used to weep all the time. I tried to cheer her up, talk to her, make her smile. I took her to the medical college for treatment. She said the place was too dark and depressing. She felt holed up* Pg 18 L 33-37 *‘I told her we also live here. Why can’t you stay for a few days? She said- ‘You’re used to living in a prison. I‘m not. I’ll be happier dying at home than staying here. She didn’t like the food either.”* Caregiver 3, Pg 2, L 30-34 (Officer caring for father with Parkinson’s disease) *“We had very limited infrastructure in those small houses. He’d say, ‘Let me go to my house. Let me stay there only. I’ve spent my entire life in these government quarters. Now let me spend my remaining days at my own home.’”* Caregiver 13, Pg 5 L 6-9 (Officer caring for mother with hemiplegia and aphasia and father with cardiac failure) *‘For father. it was very difficult psychologically. He was under tremendous pressure. In the village he has his brother, his cousins. In the village he has… his after retirement life- it is all completely finished. Now during morning walk, evening walk, he is searching for people of his own age group but hardly finds anyone’*
Work-life balance difficult	Caregiver 2, Pg 20 L 11-14 (Lady constable caring for mother with breast cancer) *“She is being treated at the cancer centre near our village…but she can’t come here and I can’t go there. I feel tied up… want to just run away and be with her. But I can’t …I can’t leave the job and go home…have the children to feed”.* Caregiver 13, Pg 10 L 31-37 *“If you spend your youth looking after your aged parents only, then how will you earn a livelihood, how will you eat? So emotional drama is also not practical. I can’t see any advantage in the force. Disadvantage is that you’re cut off from social life. Had I been in the civil, my father-mother would be living in the village. I’d also have a job nearby. There’d be some people to look after them. Family…extended family. Sister is there- her support would’ve been there. Now that I’m far away, she can’t come. Leave and transfer are always a problem.”*

healthcare expenditure is “out-of-pocket, impoverishing millions.”[39-43,50] In 2015, almost 8% Indians were pushed below poverty line, especially in rural and female–headed households,[51] similarly reported by the widows in this study.

Psychosocial and informational needs of this group align with those of caregivers in other countries.[33-38] “Caregivers may not define themselves as caregivers. For women especially, caring is simply expected as part of life.”[3] “Most caregivers feel unprepared, experience considerable stress, and[35]

Table 9: Gender issues.

Sub-themes	Quotes from interviews
Females main caretakers for majority Household work adds to caretaking	Caregiver 12, Pg 7 L 3-5 (Head-Constable caring for child with congenital hydrocephalus and Mental retardation) *'When they (mothers) take them for physiotherapy, they have to prepare the breakfast, do the morning household chores before going, Other kids come back from school and have to wait, then they go back and prepare lunch. The whole household work gets held up till that time."*
Physical effects of caretaking tasks Health issues	Caregiver 14, Pg 4 L33,34, (Officer caring for mother with hemiplegia and aphasia and father with cardiac failure) Pg 5 L 23-25 *'Mother falling sick, shifting in with us and the wife becoming pregnant-happened simultaneously. Her falling sick. their shifting in with us. The first three months of pregnancy were tough but she managed her complications and also started caring for mother. For my wife, it was physically and mentally exhausting. Sending the daughter to school, getting her homework done…lack of sleep, cooking, cleaning, bathing my mother and feeding her as well as the infant."*
Cultural issues - not allowed to travel alone Information given only to male family members	Caregiver 8, Pg 18 L8-9 (Officer, cared for father with prostate cancer) *"For the wives, it is very difficult. Most of the times, the lady is alone. They are not very educated. They may even be educated but do not have the confidence to go and talk to the doctors."*
Female, both as patients and caregivers, not involved in decision making	Caregiver 2, Pg 1 L 2, 3, 20, 21 (Widow of constable who died of AIDS) *"My husband was HIV positive. I had no idea of his illness. It was only during his last days that I came to know. He was in the unit and I did not know. No one told me - neither my husband nor the medical staff."* Caregiver 4, Pg 5 L 10-12 (Mother caring for child with Cerebral Palsy) *'They did not tell anything. They told me only that you have to keep coming for follow-up after every fifteen days. They talked either to my father or to my husband. I kept asking again and again but no one would tell me anything or ask me what I thought.'*
Harassment and ill treatment of widows Deprivation from land and property rights	Caregiver 2, Pg14 L 17-19, L 24-25 (Widow of constable who died of AIDS): *"When relatives came to visit after my husband died, my in-laws would say, 'Who knows where she's been wandering to pick up this disease!' They even said to my children- 'You are dogs, coming here to beg for food" Obviously any child would feel bad. I told my children, 'Never mind. It's our bad luck. We just have to pass the time somehow. Let people say what they want'; but they refused to ever go to my in laws' house again. They have turned my children out of their rightful share in the land and ancestral house."*

helplessness with illness progression, inability to relieve pain or decisions about admission;[34] need information and training; and are more likely to have longstanding illness or disability.[33] Stress among caregivers affects the quality of care adversely.[36]

Publications about stress in Indian armed forces reported similar factors.[52-54] In the armed forces, leave is not a right.[55] Individual rights are curtailed due to nature of duties and to maintain collective discipline. A study of stressful life-events showed-two-third of 52 events were related to leave, relocations, inability to solve family problems,[54] denial of leave when required and inadequate family accommodation;[53] with sanction of leave being pre-dominant. Community support assumes greater significance because the stressful lifestyle and wives staying alone aggravates psychosocial problems.[17,52,53]"The whole support system built up at one location is interrupted by frequent transfers and has to be built up all over again.[56] This background of pre-existing stress factors in uniformed forces adds to the complexity of psychosocial issues faced by caregivers and makes caring even more challenging.

These subjects also echo previous findings of caregiving making work-life balance difficult,[57,58] being gendered,[59-61] and Asian women facing limited autonomy[62] and discrimination.[63-65]

CONCLUSION

Arranging palliative care at home is especially challenging for caregivers from service families in rural India. Constraints of duty, frequent transfers and social isolation disrupt care. Emotional, financial, and legal problems escalate the pre-existing stress. Increasing palliative care awareness; education; and training to integrate it into existing healthcare; timely leave, awareness of benefits, implementing transfer policies fairly and increasing family accommodation can help mitigate some of the problems. BSF has the highest voluntary

Table 10: Carergivers’ suggestions.

Sub-themes	Quotes from interviews
Creating awareness of the rights and benefits entitled to force personnel	Caregiver 5, Pg 29, L 12-14 *(Constable caring for teenaged daughter with Chronic neurological disorder and mental retardation): For one year, the constable learns only drill, but what is the policy, what they can get under the policy, who is entitled to sanction these benefits, what is the procedure…they do not learn the practical things.”* Caregiver 14, Pg 8 L 9-10 (Constable caring for wife with refractory leukemia): *“The constables should be told what are the benefits entitled to them, how to get them.”*
Identifying the needy Setting up palliative care units and home-care Identifying and training staff Coordinating with NGOs Improving transport facilities Setting up support groups and special schools Institutional care for long term care	Caregiver 12, Pg 8 L 27-32 (Head constable caring for child with congenital hydrocephalus and mental retardation): *‘Now my wife, in the village… she can’t travel alone in the bus with this child. There should be some such facility with trained staff, some special buses in the campus, people with problems should be listed, have some accommodation for those with such problems in cities where there are special schools, some nursing homes, tie up with NGOs or some agencies- for those with old and sick parents so that the serving person can go back to the border and carry out his duties with a free mind”*

retirement rate in the world- mainly due to “family issues, illness of self or family and family obligations.”[66] Through listening to caregivers, professionals can better understand the embedded values, goals, joys, and disappointments connecting their lives with those for whom they care.[67] This study will help support uniformed forces’ patients and families better by understanding issues unique to forces and suggesting remedial strategies.

Strengths and limitations

The study sample represents diverse conditions; geographical and population groups across India and the themes generated are common to all. The limitations are that it is specifically about the issues facing caregivers in armed forces which have characteristic organizational and psychosocial limitations - some of which may not extrapolate well to the general population of caregivers. However, focusing on the distinct needs of this group is an urgent priority if better quality of life is going to be achieved for patients with palliative needs as well as personnel serving the armed forces. Qualitative research risks bias in the interpretation of the results. However, if conducted with meticulous attention to methodology and recognizing the reflexivity of the researcher, the quality is robust.

Areas suggested for future study are: “Assessing symptom burden,” “Changes in knowledge, awareness and practice regarding palliative care” and “Measuring caregiver outcomes” after introducing palliative care services and education in BSF.

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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