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Home Based Palliative Care

Sourav Goswami

Abstract

Palliative care aims at improving the quality of life of a patient who is suffering from a chronic serious ailment like that of advanced cancer. Nobody wants to be away from his/her own family, especially when it's known, he has limited days to live in this world. A patient gets the best treatment when it's given in his own home and that too by his close ones. When palliative care is provided at the patient's home, it provides a sense of safety, privacy, confidentiality and peace of mind for the patient. Specialist home-based palliative care improves symptom control, health-related communication and psychosocial support. It helps in better preparing the patient and the family members to accept death. It is provided by a team of trained members which includes doctor, nurse, social worker, volunteers, physiotherapist etc. They pay regular visits at the home of the patient and provide necessary health care to the patient. Considering the increasing cost of treatment of chronic illnesses, it's sometimes hard on the part of the family to continue treatment in a hospital or hospice. It's especially true in scenarios where population are not protected financially, in countries like India. The family members also play a vital role in home-based palliative care. They get trained from the team to learn the basics of palliation. Home based palliative care needs to be integrated into regular home health care services.

Keywords: palliative care, home based, quality of life, Home PAL

1. Introduction

In today's world, non-communicable diseases like cancer, dementia, renal failure etc. are increasing in leaps and bounds. They need long term care for their chronic condition [1]. It has been estimated that around 1.5 billion people experience chronic pain round the world, and an estimated 61 million people endure unrelieved serious health-related suffering globally [1–3]. Many of them result in increasing morbidity making patients critically ill. Death is inevitable, but, today's era is giving more importance to the quality of life lived than its longevity [4]. Here comes the role of palliative care, which helps improve the quality of one's life especially in his last days and tries to decrease the burden of the disease. World Health Organization (WHO) has defined Palliative care as an approach that improves the quality of life of patients and their families experiencing problems related to life-threatening disease [5]. It is provided through the prevention, assessment and treatment of pain and other physical, psychosocial and spiritual problems.

In general, palliative care mostly functions in hospitals where the patient is admitted or may be in day care basis, where the patient needs to pay a visit to the hospital on regular basis for some procedures or sessions that help in alleviating their pain and other symptoms. Palliative care should be an admixture with the curative form of treatment which should begin from the early part of patient

management. The patient, especially in his end stage of life, is happy to be with his near and dear ones, in his known home environment. This has built up the foundation of the concept of Home based palliative care (Home PAL) [6].

2. Understanding ‘Home based palliative care’ (Home PAL)

Home PAL is a form of palliative care that provides all the basic needs (physical, psychological, and moral) to the patient who is suffering from a chronic debilitating disease like advanced cancer, lung, renal, cardiac disease or may be dementia [7], in their homes or in a homely environment. The Home Pal is provided by a trained multidisciplinary team of doctors, nurses, social workers, physiotherapists, volunteers and others as per the need of the disease progression. The care provided by the team is at par with the standard palliative care practiced in the hospitals, institutions or hospices [8].

Teams of doctors, nurses, social workers and chaplains travel primarily to patients’ homes and also to the rehabilitation centres and help in long term care of the patients, who are suffering from terminal illnesses.

3. Importance of home PAL

3.1 For the patient

The general principles of Palliative care [9] hold good in case of Home PAL as well, which can be briefly narrated as follows:

- Controlling the distressing symptoms of illness, like pain relief, etc.
- Independence.
- Intends neither to hasten nor postpone death. Rather it provides emotional, spiritual and cultural wellbeing to the patient.
- Planning for the future.
- Preparing oneself for the inevitable – death. Affirms life and regards dying as a normal process
- Will enhance quality of life, and may also positively influence the course of illness
- Caring for their family and carers.

But, to achieve those stated above, the patient should be at his peace of mind. Peace of mind comes, when he dwells in a peaceful environment which he is accustomed with since long – his own home. No one wants to die alone. Everybody wants to have his near and dear ones by his side when he is in his death bed [10].

The patient gains more confidence, when he is getting his treatment in his homely environment, where the family members are taking an active part in the process of the therapy.

3.2 For the caregiver

A person suffering from any chronic critical illness is in a debilitated state. He is not in a position to take care of himself. There comes the role of family members

who come forward to take care of their loved one. Informal care by family members is unique in developing countries like India when compared with the developed world where care giving is usually in the form of paid formal care. But, this transition from being a close relative to a caregiver occurs so quickly that many a times they are not prepared for it. While providing care for their ill loved one, who is in his death bed, caregivers often neglect their own needs. This neglect, over time, comes as a heavy toll on the overall well-being of a caregiver and they feel stressed – physically, emotionally and financially [11].

That is the reason why quality of life of patient's families has been included in the WHO's definition of Palliative care. The family members are at ease, when the patient receives treatment at home. It saves their time and money in traveling to the hospital. They can continue their regular chores and at the same time they can also learn and get trained from the expert team of Home PAL, few of the basic measures of providing palliative care like giving the proper medicine at proper time, providing physical and psychological support when needed. This helps in building confidence among the family caregivers [12]. They feel happy when their work (in the form of patient's care taking) gets recognized and they feel that their minor help is making a major impact in the quality life of the patient.

The home-based care services ensure continuity of care for patients and empower the caregiver in the family by teaching them simple and cost effective methods of patient care.

4. Things to be done to set up Home PAL

Home PAL service can be set up in a quite simple manner. The following are a gist of activities to be performed to set up the home based palliative care [13].

Like any program to be launched, we need to conduct a need base evaluation for the home based palliative care. It will help us to identify the beneficiaries, their requirements and to check if we have enough logistics to support the program. Logistics will be in term of man, material, money and time.

Once the team or the institute is satisfied with the basic evaluation, competent authorities need to be involved, informed and necessary permissions need to be taken. There is a need for setting up a formal office for the Home PAL.

Now, the action plan needs to be framed, scanned, verified and edited. This includes the resource based evaluation and what all services should be included in the charter needs to be finalized.

The Home PAL team needs to be trained efficiently in palliative care. It would be best if a trained nurse and a trained doctor can be included in the team, to begin with. If not, the dedicated team needs to get trained from a dedicated training center of palliative care.

The goal of home based palliative care is to involve community volunteers in the team. So, the community volunteers needs to be identified and proper training needs to be undertaken. The resource based evaluation, as described earlier should include the financial requirement for purchasing the necessary supplies, transportation costs and salary of the Home PAL team.

In Home PAL, the team needs to travel to the homes of the patients, which will be away from the mother institute or hospital. So, the primary care team or health workers, both government and private, need to be contacted and should be included in the community based Home PAL team. It will help in emergency care and support to the ailing patient, in times, when the Home PAL team will not be available. Also, it will help in quicker diagnosis of any emergency and better management including referral to higher centers.

IEC (Information Education Communication) and BCC (Behavior Change Communication) has a great role to play in the success of the Home PAL program. It calls for involving the public health personals, both government and private, who work with the community of that locality. The media needs to be involved as well, for better propagation of the news and information of the Home PAL. Home PAL calls for a wider support and participation from the whole community including the villagers, students, political leaders and governmental staff, for the program to succeed in achieving what it aims to do.

5. Components of Home PAL

To carry out Home PAL, we need to have a dedicated team, trained in palliative care. The patient's need to be identified beforehand. The local volunteers needs to be recruited. They are the contact persons, who would inform the households regarding the date and time of visit of the Home PAL team. Many a times, a member of the Home PAL team may directly contact a family member of the patient and inform him of their time of visit. So, the house hold should possess a mobile or a telephone for easier contact. The home environment should be a safe and accessible place for the team to store drugs and equipment, as well as to talk to the patients and family members to plan for their treatment. The dedicated space in the house for storing medicines should be a safe one outside the reach of children and the patient. They should also carry a basic set of medicines in their home care kit, including morphine to refill the stores at home. Documentation should be properly done. Home PAL forms should be prepared. It will help in proper documentation and recording of the patient details. It should include the consent form, that needs to be read and explained to the caregivers and their signature needs to be taken. The forms should also record the medicines prescribed to the patients with detailed dosage and schedule. A separate 'morphine register' should be maintained to have a note of the correct number of morphine tablets dispatched to the patients. It should be compliant with the local laws and regulations.

Importantly, in order to implement home PAL; the health care team, the patient and the family must agree that the patient can be adequately managed at home, and the treatment plan should be approved by all the stakeholders.

Now, let us come to each of the components in details.

5.1 The Home PAL team

A full-time nurse and a part-time doctor are the minimum requirements for a home-care team, although this depends on the regulatory and health system norms in the country. A multidisciplinary team of nurses, doctors, psychologists/counselors, social workers and trained volunteers or community health workers is ideal ⁶.

5.2 Requirements

The requirements are tabulated in **Table 1**, under the headings of basic infrastructure, personnel, home care kit and finance [6].

5.3 Home care kit

The Home PAL team should carry with them a basic home care kit, which includes some basic medical instruments, medicines for managing acute as well as chronic complains, dressing materials and nutritious supply [13, 14]. They are mentioned in details in **Table 2**.

Basic Infrastructure	Central meeting point
	Storage facilities (including for controlled drugs)
	Transport of team and home care kit
	Method of communication (telephone, mobile, etc)
Personnel	Doctors
	Nurses
	Volunteers etc.
Home care kit	Medication (including morphine)
	Equipment
	Documentation
Finance	Salaries for team members
	Transportation/vehicle hire
	Rental for room/storage facility
	Communication and printing
	Medication and equipment costs

Table 1.
Requirement for Home PAL set up.

Medical equipment and supplies	Stethoscope
	Sphygmomanometer
	Thermometer
	Tongue depressor
	Forceps
Supporting equipment	Alternating air mattress
	Aspirator
	Nebulizer
	Wheel chairs
	Walking aids
Tools	Dressing materials
	Cotton
	Scissors
	Gauze
	Gloves
	Plaster
	Transfusion materials
	IV infusion sets
	Cannula and butterfly needle
	Injector and needle
	Aspirator probes
	Urinary catheters
	Bladder
	Feeding tubes

Medicines	
Pain management	Paracetamol
	Ibuprofen
	Diclofenac
	Codeine
	Tramadol
	Morphine
	Gabapentin
Gastrointestinal symptom management	Metoclopramide
	Domperidone
	Dexamethasone
	Bisacodil
	Loperamide
	Oral rehydration salts
	Ranitidine
Psychological symptom management	Diazepam
	Haloperidol
	Amitriptyline
Antibiotics and antifungals	Ciprofloxacin
	Metronidazole
	Oxacillin
	Fluconazole
Wound therapy	Betadine solution and ointment
	Metronidazole gel
	Hydrogen peroxide
Nutritional supplements	High protein and calorie food supplements
	Iron, vitamin and mineral supplements

Table 2.
Home care kit.

	Basic	Mid level	Advanced
Doctors	Foundation courses (3–10 days)	Resident course (6 weeks)	Fellowship/Post graduate qualification in palliative care (1–3 years)
Nurses	Foundation courses (3–10 days)	Resident course (6 weeks)	Certificate course (4 months), fellowship (1 year)
Community health workers	3–6 hours to supplement prior training	Basic course (3 months/400 hours)	Advanced communication skills/ lymphedema management
Volunteers	Introductory course (3 hours)	16 hours theory + 4 clinical sessions,	Advanced communication skills and train-the-trainer course

** Note: Minimum requirements for home-care team depend greatly on the format of the health system. There are countries where nurses play a larger role, and others where home care is conducted more by doctors.*

Table 3.
Training requirements for the Home PAL team.

5.4 Trainings

The suggested minimum training for various members [6] of the home-care team is described in **Table 3**.

6. Role of telemedicine in Home PAL

Telemedicine, which literally means ‘healing at a distance’, is the practice of consultation, care, diagnosis and interaction between the physician and the patients, who are located remotely via different technologies which involves video conferencing [15]. The world has evidenced the grievousness of covid crisis, where it’s either risk taking to visit a hospital or it’s difficult to arrange transportation every time due to the occasional curfews and lock downs. In such a scenario, the use of technology in the form of telemedicine is surely appealing to be used for palliation as well in the home set ups. It is evidence based that telemedicine has been used to be a success in different parts of the world, especially in the European countries [16]. Telemedicine while used for palliative care has proven to improve the symptoms, quality of life and care for the patient and also results in better satisfaction to the patient and the caregiver. It also saves the doctor’s time. But the most important hurdle of using telemedicine round the globe is the technology related complications. To describe briefly, most of the patients eligible for palliative care are elderly, many of them are not techno friendly. There lacks proper connectivity of internet and electricity in most of the developing nations including India, which is a must for a successful telemedicine set up [17, 18]. Though in urban areas, things could be manageable, but the scenario is just the reverse in rural set up. Moreover, there always remains a difference between the in person care and the tele care provided by the councilor or the Home PAL team, when the patient is in his last days of life. Once these challenges are taken care of, there are prospective avenues to incorporate telemedicine in the regular Home PAL services.

7. Benefits

- i. Patients are more comfortable in their own home than in a hospital set up [19].
- ii. In Home PAL, family members are directly involved in the process of palliative care. So, patient has an easy access to care.
- iii. It provides training and support to family members to help them develop as caregivers.
- iv. The home PAL team is able to facilitate quick referral to additional services.
- v. Privacy and confidentiality is maintained when the care is being carried out in the home of the patient.
- vi. It helps to increase community awareness of palliative care. Local resources and support networks can be mobilized and training can be provided by community health workers to others in the local area [5].
- vii. Saves traveling cost and time for the patient and his family.

- viii. Considering the increasing cost of treatment of chronic illnesses, it's sometimes hard on the part of the family to continue treatment in a hospital or hospice. It's especially true in scenarios where population are not protected financially, in countries like India.

8. Limitations

- i. One of the limitations is to convince the patients and their families to call the care team when they experience a health crisis, for which, the Home PAL team need to build trust and rapport with the patients and their families [20].
- ii. Family members may not be prepared to bring the patient to hospital in times of urgency. So, Home PAL team needs to develop preparedness among the family members to shift the patient to health care facility whenever required, which calls for advanced arrangement of money, transportation and people who will be accompanying them to hospital. Scenarios can get worse in current pandemic situations of Covid.
- iii. The providers of the home PAL needs to be very sincere in paying the home visits in order to avoid care fragmentation and should never fail in their routine.

9. Best practice – example from Kerala, India

Kerala is pioneer in community-based palliative care through a socially innovative approach called the Neighborhood Network in Palliative Care in an attempt to develop a free of charge, sustainable, community led service capable of offering comprehensive long-term care and palliative care. The network aims to empower local communities to look after their chronically ill and dying patients. Funds for running the programme are raised locally by volunteers [21].

The programme was first pilot studied in 1996 in Malappuram, located in the northern district of Kerala, the state with the highest literacy rate in India. It was run by community based organizations. It was first started for cancer patients. The program was gradually expanded to include other patients who required long-term care and support such as stroke, alzheimer's disease, paraplegia and psychiatric conditions. Volunteers from the community were selected and were trained to identify the psycho-social needs of people with chronic disease in their area in order to intervene effectively with active support from a team of trained health care personnel [21, 22]. The nurses who were trained in palliative care played a vital role in this. They regularly visited the home of the patients who were enrolled in the program and provide nursing care and support at home, which included wound dressing, catheterisation, nasogastric tube insertion, and counseling. The doctors were called only for selected patients where the patient needed a physician's consultation, which was chartered by the palliative care nurse. The community volunteers also played an important role. Trained by the palliative team with the first-hand knowledge of basic nursing and palliative care, they helped patients and their families financially and emotionally. The model was a successful one. It inspired the state of Kerala to implement a palliative care policy to ensure universal coverage of palliative care services in all its local administrative units, making it the first state in Asia to develop such a policy. Home based care was considered as the corner stone of palliative care services in the policy implemented [23]. The Neighborhood Network in Palliative Care in Kerala is the best example of a community-based palliative care for low-resource countries in the world.

10. Conclusion

Considering the increasing number of critically ill patients who are in need of palliative care for long, it is high time to focus towards implementing home based palliative care measures that will help patient maintain their quality of life. It should be emphasized to include palliative care, especially home based palliative care in the primary care, community and home based health care services. Gradually, it is necessary to create and implement National health policies that integrate Home PAL services into regular home health care services.

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