

Palliative Home Care: A Designer's Perspective

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ABSTRACT

The purpose for this observational research was to understand how Can Support provides palliative care at home and analyze its strengths and weaknesses in various socioeconomic scenarios for future development. In the period of 2 weeks, patients and their caregivers were silently observed in their natural surroundings during home care visits in order to listen their problems, identify the pattern of questions for the home care team, their natural way of storytelling, organizational techniques for medicines and medical reports, care givers lives, patient journey, etc. Such observations have enabled the understanding of the phenomena of home palliative care and have led to the identification of certain influential variables of the practice.

Key words: Home care, observational research, palliative home care

MATERIALS AND METHODS

In this research period, 17 cases were observed. Out of which 13 were of post cancer surgery cases, two were a bereavement visits, one was a Parkinson's disease patient which needed psychological counseling, and one was an advanced stage chronic renal failure patient.

In all visits, sufficient time was dedicated to observe and understand the interactions, problems, and confusion among the persons in the patient room. The observations were silent and nonparticipatory, in view to keep the patient and the informal caregiver comfortable and have regular and unbiased conversations with the home care team.

OBSERVATIONS

The central observation was that home care is a total paradigm shift from the conventional hospital

consultation settings. Home care shifts the center of gravity from the doctors/hospital to the patients and their caregivers.

The following points enlist the main observations from the field visits:

- Time is not the main constraint in home care. At homes, the patients and their family are in their comfort zone and lead the discussion at the required occasions. There is always a personal touch in the care delivery process, which is outstanding from the point of view of the care receivers. They have the time to explain their entire story in the comfort of their home. As a result, there are extensive, elaborative, and in-depth conversations making the decision-making process for the doctor and councilor is more comprehensive. The home care team is like a considerate friend who is from the medical world and is present to help people at their homes for no material returns
- The quality of care delivery depends majorly on the primary informal caregiver. In almost all situations, it was the spouse. In certain scenarios, it was the daughter/son or daughter-in-law. The instruction/information and education they knew was from the hospital mainly from the time the patient was admitted. Very few tried to learn more on their own form the internet and other resources. Home care

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teams had privilege and the duty to provide regular, frequent, and contextual counseling to the caregivers, which they could easily grasp and perform

- A major amount of time and energy of the home care team is spent in counseling the informal care giver about medication and diet. In almost all cases, medication was the single greatest factor for confusion. Literacy and management sense was instrumental in organizing the medication for the patients.

However, in some situations, the prescriptions were either tweaked to the comfort/demands of the patients or due to the availability of funds or were completely chaotic and disorganized due to immense confusion and frustration. As a consequence, the patient suffered and naturally their condition constantly deteriorated.

Through the observations, the main reasons for lack of medication adherence could be the following:

- a. Confusion and organization: Patients are expected to take over 15 medicines every day at different times. They have complex prescriptions with different medicine combinations. Remembering through color, size, time, and effect was the most common technique to recall doses
 - b. Confusion in care coordination: The medication prescription of the oncologist/specialist and home care doctor at times are incoherent leading to conflicting doses and times. This naturally creates a sense of uncertainty and confusion
 - c. Lack of hope: If the disease is at its terminal stage, people often lose all hope in medicines. They may start giving in to the disease or try alternate techniques like homeopathy, ayurvedic, etc
 - d. Self prescriptions: Many have made up their minds on certain medicines being either useless or extremely beneficial; psychologically drifting away from the actual virtue of the medications. Hence, such practices at times led to illogical doses, overdose, and physical complications like constipation and lack of appetite. Monitoring such activities is also extremely important and right education in meaningful ways needs to be provided to the caregivers and the patient in such scenarios.
- Almost all families fighting a chronic disease like cancer were in need for emotional and psychological counseling. It is a dramatic life event for the patient and demands a lot from the informal caregiver in terms of learning new and complicated procedures in providing care, nursing, and counseling to the patient and other family members at home. The patient is under a lot

of suffering as their lives take a dramatic turn. Their dignity of life is rusticated and they are now completely dependent, in the hands of their caregivers. Palliative home care is not an easy job. It is mentally, physically, and emotionally taxing for the patients and their caregivers

- Certain nursing issues can also be contextually demonstrated and explained in the home care. It provides much better understanding for the informal caregivers to provide care themselves in the right way, empowering them to do the best of their abilities with confidence. This eventually leads to a greater sense of satisfaction and empowerment, being able to help their loved ones
- A major amount of discussion between the informal and formal caregiver commences and develops on the reports from the hospitals. The test reports, discharge summaries, and medication prescriptions are the most important underlying information for the home care team to get hold of the case. The organization of such information is in the hands of the caregiver. Generally, it is done in the conventional clerical filing method to make the information organized and accessible.

The requirement of such documents is more during the initial visits and after long gaps (monthly patients). Patients under frequent consultation already are in a momentum for care delivery and regular consults.

RESULTS/SUGGESTIONS

The results of the observational research have been compiled in a strength–weakness internal analysis of the home palliative care approach of the organization. The following strengths and weaknesses are intrinsic to the organization and wherever necessary, relativeness is mentioned.

Strengths

- Personal touch in care delivery
- Time dedicated for counseling
- The balance of medical-nursing-psychiatric counseling
- Comprehensive patient history documentation
- Contextual immediate solutions
- The relations that are built.

Weaknesses

- Low efficiency: Each visit must have a clear agenda. The caregiver/patient must be encouraged to speak, but the home care team should be in control of the discussion and must touch upon the required points. In real-time, it is natural that discussions may stay away

from the agenda. This is not discouraged, but the team should know when to move on

- Approach to medication organization: The home care team can better help the caregivers to manage the medications by providing access and training to use certain simple tools like charts/pillboxes, etc
- Nursing education: The organization could organize some sort of nursing training workshops for the informal caregiver using the day care infrastructure. Perhaps a bit of teaching/demonstration/workout can be much more beneficial than mere words
- Feedback mechanism: The feedback loop can be made more efficient. The home care teams have little idea if the caregivers are able to manage the counseling/advice. The scenario is a bit 'reactive' in terms of consultations, as it depends on the caregiver's call for problems. It should be improved and made 'proactive' for better results.

CONCLUSION

The organization is already well-established because their home care teams put in their most dedicated effort to

improve the quality of life of the family fighting a chronic disease. The balance of medical, nursing, and emotional support is an excellent patient-centred model for care delivery.

Though there are certain points, which could be considered for improving the working of the home care teams in various scenarios, it is already well-equipped and does a great job.

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